



From
hospital to home

Guidance on discharge management
and community support for children
using long-term ventilation

Jane Noyes and Mary Lewis



Barnardo's

GIVING CHILDREN BACK THEIR FUTURE

From Hospital to Home

Guidance on discharge management and community support for children using long-term ventilation

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Published by Barnardo's
Tanners Lane
Barkingside
Ilford
Essex
IG6 1QG

Charity registration number 216250

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A catalogue record for this book is available from the British Library.

ISBN 1 904659 14 4

Barnardo's vision is that the lives of all children should be free from poverty, abuse and discrimination.

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'To look into some aspects of the future, we do not need projections by supercomputers. Much of the next millennium can be seen in how we care for our children today. Tomorrow's world may be influenced by science and technology, but more than anything, it is already taking shape in the bodies and minds of our children'

Kofi Annan, Secretary General of the United Nations, UNICEF convention, www.unicef.org
27/02/05 ('Special case for children')

Acknowledgements

We are grateful to the parents and children who have provided feedback and insights from their perspective. In particular, we would like to thank Linda Middleton (CCHS Family Support) for distributing early drafts to parents and commenting on various drafts that helped to shape the final guidance.

This guidance draws heavily upon existing examples of best practice relating to the discharge and ongoing management of children who require long-term ventilation. Numerous professionals have provided us with examples of documentation currently used in clinical practice, and expert guidance. This is intended to point practitioners and professionals in the right directions, enabling them to build their practice on foundations that are as sound as possible at this time. Although it is not possible to acknowledge all of the individuals whose skills and expertise have contributed to this project, there is no way that we could have completed this work without their support. Many of the professionals who made a significant contribution to the development of this work are part of a clinical network called the UK Long-Term Ventilation Working Party, which is chaired by Dr Colin Wallis (Great Ormond Street Hospital for Children NHS Trust). In particular, Dr Martin Samuels read and commented on various drafts (University Hospital of North Staffordshire). In addition, members of staff who contributed include, in particular, Sally Beckley and Sarah Leggett, from the Lifetime Service, Bath, who provided valuable input to the development of the care pathway, and Jan Morrison from the Policy and Research Unit at Barnardo's who managed and supervised production of the guidance.

Finally, we are grateful to the Department of Health for commissioning this work.

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All documents, policies, guidelines and procedures that are referenced in this guidance and/or available to download from the document store on the 'UK Children on Long-Term Ventilation' website have been provided as examples of current best practice by practitioners, NHS Trusts, private and voluntary sector organisations with experience of managing children requiring long-term ventilation. All documents have been designed for local use within a specific context. No quality appraisal has been undertaken of any of the documentation received. All documents, policies, guidelines and procedures should be adapted for local use taking into consideration: the specific context; available research evidence; the manufacturer product licence and instructions for use, if appropriate; and local clinical governance and risk management frameworks.

Foreword

I am very grateful to the families, and to the many health and social care professionals who have worked closely with Barnardo's to take forward this work on preparing for and supporting children requiring long term ventilation in the community.

Although options for discharge must never be rushed, there is no reason why a child's move from hospital to home should be delayed because of a lack of familiarity with procedural arrangements and considerations. This guidance highlights an essential understanding of what is involved, with links to further sources of information to provide that children and families receive an individual care package which is right for them and accords with best practice.

The care pathway described in the guidance has been adopted as an exemplar within the National Service Framework for Children range of documents, to stimulate local debate and assist multi-agency partners to re-evaluate the way they collaborate on, commission and deliver children's services. The guidance, and the exemplar which it provides, illustrates a very positive but very real perspective on what can be achieved by a cohesive and inclusive strategy. I am happy to commend it.

LIAM BYRNE

Parliamentary Under Secretary of State for Care Services.

Contents

Acknowledgements	iii
The authors	iv
Copyright and Disclaimer	v
Foreword	vi
Introduction	1
Section 1 Core principles underpinning the organisation and delivery of care	4
1.0 The organisation and delivery of care: NHS, voluntary and private sector partnerships	4
1.1 Children's rights and equality of access	4
1.2 Key working and multi-agency working	5
1.3 Sharing best practice	7
1.4 Parent and child involvement	7
1.5 Risk management and clinical governance	8
1.6 Safeguarding children	9
References	9
Section 2 Exemplar care pathway for discharge management and community support	11
2.0 Introduction	11
2.1 The discharge process	12
2.2 Living at home	28
2.3 Growing up and transition	38
Section 3 Hints, tips and tools for applying the care pathway locally	40
Contents of Section 3	
3.0 Introduction	40
3.1 Planning for discharge of a child from hospital	40
3.2 Delivering care in domestic settings	85
3.3 The young person's changing social needs and sexuality	97
3.4 Transition to adult services	98
3.5 Implementing cross-department national policies to improve outcomes for children with complex needs	98
References	101
Bibliographies	
A) Definitions, key policy documents and service specifications	104
B) Assessment frameworks and discharge management	107
C) Human resources	109
D) Clinical governance, risk management and child protection	111
E) Key working, inter-agency and multi-agency working	113
F) Education	115
G) Housing, equipment and adaptations	116
H) The roles of parents and carers in domestic settings	117
I) Clinical guidelines	119
J) Medical/self-management and follow-up	121
K) Transition	122
L) Economic issues	123
M) Social inclusion, involving children and their families, expert patients and short breaks	124
Useful contacts	126

Boxes

Box 1	Indications for long-term ventilation	1
Box 2	The Lifetime Service Proforma: multi-agency care package proposal for the child with complex health needs	46
Box 3	Key goals in discharge planning	57
Box 4	Example of a checklist for discharge planning	58
Box 5	Examples of factors that may influence parents' roles	64
Box 6	The five steps in the process of risk assessment	76
Box 7	Example of a risk-assessment template, plus information on scoring risks	78
Box 8	Government cross-department policies and initiatives to promote Rachel's social inclusion	100

Tables

Table 1	An example of costings for Rachel's first year of care	48
Table 2	Total costs of support for 24 children living at home over the previous 12 months, 2002 prices	50
Table 3	Comparison of total costs of 12 months support in different hospital and home-care settings, 2002 prices	52
Table 4	Summary and costs of core equipment that may need to be purchased	69

Introduction

Long-term ventilation is now an increasingly frequent and usually high-cost intervention for babies, infants and children who have a range of diagnoses and whose impairments span the entire spectrum from simple to complex. In 1998, the UK children's long-term ventilation working party defined long-term ventilation as:

'Any child who when medically stable, continued to need a mechanical aid for breathing which may be acknowledged after a failure to wean, 3 months after the institution of ventilation'
(Jardine and Wallis, 1998)

The main indications for long-term ventilation are summarised in Box 1 (this list is not exhaustive).

Box 1 Indications for long-term ventilation (adapted from Samuels, 1996)

High cervical trauma

- Road-traffic accident
- Birth injury
- Non-accidental injury

Neuromuscular disease

- Spinal muscular atrophy
- Congenital myopathy
- Leigh's disease
- Duchenne Muscular Dystrophy

Congenital Central Hypoventilation Syndrome (CCHS) (Ondine's)

Infection

- After encephalitis or myelitis

Tumour, after surgical resection

Congenital brain malformation

- Arnold-Chiari
- Vascular malformations

Chronic lung disease

- Bronchopulmonary dysplasia
- Cystic fibrosis

Airway obstruction

- Congenital malformations
- Morbid obesity

Children use different types of ventilation according to their underlying medical condition, ranging from non-invasive via a face-mask to invasive via a tracheostomy. In addition, children have different requirements for ventilation ranging from whenever they are asleep to 24 hours a day. For more information on these clinical issues, see for example Samuels (1996) and Noyes (1999a) who provide a comprehensive overview of the types of ventilation available and their application.

The numbers of children who use assisted ventilation have been rising steadily over the past decade, and healthcare professionals have worked hard to increase levels of expertise in managing these children (Jardine and Wallis, 1998). A number of policy initiatives, including a National Service Framework (NSF) for Paediatric Intensive Care (entitled *Paediatric Intensive Care: a 'Framework for the Future'*: DH, 1997a; b) have aimed to improve service provision and increase the effectiveness of discharge management. (See Bibliography A for a comprehensive list of policies and initiatives.)

Despite these policy initiatives, one of the most challenging aspects of improving the quality of services and the experience of children has been the lack of widespread implementation of best-practice guidance in the assessment of need, the organisation of discharge of children from hospital and the effective continued management of a package of services to enable children and their families to live as near ordinary lives as possible at home.

Barnardo's *Breathing Space* report (Ludvigsen and Morrison, 2003) highlighted these issues concerning the generally low quality and sporadic coverage of service provision. In particular, the case studies featured in *Breathing Space* found that children, especially those with the most complex needs for health and social care, were experiencing prolonged periods of hospitalisation when they neither had a continuing medical need to be in hospital nor wanted to be there. In addition, children and families reported that without focused, high-quality and continuing support, they experienced overwhelming caring responsibilities and became isolated socially.

Focus and purpose of this supporting guidance

The focus of this guidance is on children whose needs are at the more complex end of the spectrum. This guidance includes an exemplar containing a care pathway on the discharge and ongoing care management of a child requiring long-term ventilation. Both the exemplar and this supporting guidance have been compiled to assist multi-agency commissioners in the new commissioning environment, managers and practitioners working in the statutory, voluntary and private sectors in improving both discharge policy and practice, and the experience of community support for children and young people requiring long-term ventilation. Implicit to the exemplar and this supporting guidance is the requirement for a multi-agency approach. The exemplar and supporting guidance will also be of interest to parents and young people who use assisted ventilation.

The guidance is based on the National Service Framework (NSF) for Children (England), research evidence, best practice and current thinking (DfES, DH, 2004a–e). It builds on the Barnardo's *Breathing Space* report, the work of the UK long-term ventilation working party, NHS Trusts, and voluntary and private sector organisations. It is acknowledged that not every child or young person will follow the same journey or have the same type or severity of condition as the one that is illustrated in the exemplar. The legislation mentioned in this book mostly refers to provision for England.

As supporting material for the exemplar on long-term ventilation, this guidance embraces the notion of a patient journey to illustrate some of the key themes that are a feature of the lives of this group of children and their families. In line with the NSF it is hoped that this guidance may be useful to:

- highlight further references which relate to evidence in the NSF and elsewhere including, where available, key clinical guidelines
- stimulate local debate and assist multi-agency partners to re-evaluate the way they collaborate on, commission and deliver children's services, for this and other conditions, to benefit children and their families
- provide an aid to examining and improving local clinical and non-clinical governance
- provide a multi-disciplinary (training) tool for staff working with children and young people to raise awareness of specific issues and stimulate discussion
- provide a template for discussion prior to development of local strategies for managing children with complex continuing healthcare needs.

Structure of the guidance

The guidance is divided into five sections.

- 1 Core principles underpinning the organisation and delivery of care.
- 2 The NSF exemplar outlining the care pathway for the long-term ventilated child with Congenital Central Hypoventilation Syndrome (CCHS).
- 3 Hints, tips and tools for adapting and using the care pathway locally.
- 4 Bibliographies of references and other sources of information, on specific topics, and containing references or links to best-practice policies, procedures and clinical documentation.
- 5 A list of contact details for statutory and voluntary organisations working in this field, and who can provide related services or information.

Many of the materials in the bibliographies can be downloaded from the document store on the 'UK Children on Long-Term Ventilation' website (www.longtermventilation.nhs.uk) or other websites, and web details are included in the bibliographies.

Section 1

Core principles underpinning the organisation and delivery of care

1.0 The organisation and delivery of care: NHS, voluntary and private sector partnerships

This Section summarises the six core principles that underpin the organisation and delivery of the care outlined in the exemplar care pathway presented in Section 2.

There are a number of models used by the National Health Service (NHS) to commission and deliver services to children and their families. These models range from NHS provision alone, through a mixture of NHS, voluntary and private sector partnerships to deliver services, to a contract negotiated with a private sector company to provide an entire package of services including discharge management, provision of home carers and ongoing care management. Whatever the local agreement concerning the commissioning and provision of services to enable a child to live at home, the same core principles should apply to the organisation and delivery of care. There are six core principles outlined in the following sections.

1.1 Children's rights and equality of access

Children using long-term ventilation are entitled to the same opportunities as all other children but, alongside other disabled children, they face a number of barriers to exercising their basic human rights. Known barriers include prolonged and unnecessary hospitalisation, being unable to communicate, having to depend on others, and social and educational exclusion (Noyes, 2004).

The imperative for children and young people who are disabled or have complex needs to have their rights acknowledged and to be socially included is well documented (see Bibliography A). Children who require long-term ventilation support may or may not be disabled, but have the same range of needs for services and support as other disabled and non-disabled children. However, they also have additional care needs specifically related to the use of technology. They are alive through the use of complex technical equipment and the skilled intervention of highly trained carers. There can be a tendency to adopt a protectionist approach to their care; however, there is a need to balance children's vulnerability with a shift to a rights-based approach to their lives.

Standard 8 of the National Service Framework for Children sets out the responsibilities of multi-agency commissioners and service providers towards disabled children under the Disability Discrimination Act (1995, 2005) and the Special Educational Needs and Disability Act (2001). In accord with all children and young people, children who require long-term ventilation, have a right to be supported to participate in family and community activities, with facilities and access to services that are culturally competent and sensitive. The ability of children on long-term

ventilation to lead ordinary lives and enjoy their childhood requires partnership between the children, their families and joint agency working crossing traditional boundaries. The approach to achieving inclusion for this group should seek to ensure that in every setting there are appropriate education, training, protocols, procedures and permissions in place to meet the child's needs. The Bibliography includes more information on sources of additional best-practice guidance on these matters.

The particular challenges to achieving 'ordinary' lives for this group of children and young people relate to their dependence on equipment, carers, transport and finances. The nature of the medical condition and extent of ventilation required (day and night or just night-time, for example) will influence their freedom and ability to develop friendships or participate in play and leisure activities. For example, if a child requires a carer with them at all times to support their medical needs, they will lack privacy and potentially have difficulties in establishing peer relationships. Their need for peer and social support can be significant and the challenge is to create an environment in which they can make and break friendships.

As with all services for young people, a unique feature is the need to recognise that children grow and develop, and at each stage to develop supportive, timely and appropriate interventions to ensure that the young person can continue to access appropriate services and resources so they may be as fully included as possible.

The UN Convention on the Rights of the Child

In order to promote equality of access, children's rights as set out in the Articles of the United Nations Convention on the Rights of the Child (United Nations, 1989) and Human Rights Act (1998) must be met. Professionals need to be conversant with Human Rights legislation to bring about best practice and better outcomes for children. This is particularly important as parents commonly use the Articles as the legal basis for obtaining resources for their children. A summary of the Articles can be downloaded from www.longtermventilation.nhs.uk; further reference should be made to the full convention (United Nations, 1989; www.unicef.org/crc/crc.htm).

1.2 Key working and multi-agency working

At the heart of the Government's modernisation agenda is a fundamental change in philosophy about how health, social and education services should be delivered. This involves a cultural change in the way in which services are designed and delivered around the children using the services and not the organisations delivering the services. There has been a raft of cross-department policy developments to bring about multi-agency working and integration within disabled children's services generally. All are aimed at providing seamless services that start from user need and that involve children and young people who are dependent on ventilators and their families. Of particular importance to this group of children are two major policy initiatives:

1. Every Child Matters: Change for Children is a new approach to the well-being of children and young people from birth to age 19 (www.everychildmatters.gov.uk). The Government's aim is for every child, whatever their background or their circumstances, to have the support they need to:

- be healthy
- stay safe
- enjoy and achieve through learning
- make a positive contribution to society
- achieve economic well-being.

This means that the organisations involved with providing services to children – from hospitals and schools, to police and voluntary groups – will be teaming up in new ways, sharing information and working together, to protect children and young people from harm and help them achieve what they want in life. Children and young people will have far more say about issues that affect them as individuals and collectively.

2. The National Service Framework for Children sets out standards for children's health and social care, which promote high quality, woman and child-centred services and personalised care that meets the needs of parents, children and their families (www.dh.gov.uk). The first five standards apply to all children:
 1. Promoting health and well-being, identifying needs and intervening early.
 2. Supporting parenting.
 3. Child, young person and family-centred services.
 4. Growing up into adulthood.
 5. Safeguarding and promoting the welfare of children and young people.

Standards 6-11 apply to specific groups of children:

6. Children and young people who are ill.
7. Children and young people who are in hospital.
8. Disabled children, young people and those with complex health care needs.
9. The mental health and psychological well-being of children and young people.
10. Medicines for children and young people.
11. Maternity services.

See Bibliography A for full policy details.

Both 'Every Child Matters: Change for Children' and the National Service Framework for Children emphasise the importance of key and multi-agency working as core principles underlying all aspects of care planning and delivery. Standard 8 of the NSF outlines the standard whereby children receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible enable them and their families to live ordinary lives. There is a wealth of evidence relating to the positive impact of a key worker with sufficient authority on managing complex packages of care that are delivered by different agencies (see Appendix E for a comprehensive list). The report "Life Chances for Disabled People" from the Prime Minister's Strategy Unit (2005) recommends that the provision of a key worker should be considered as a key performance indicator. Further guidance on how to bring about effective key and multi-agency working is provided in sections 3.1.7, 3.1.8. and 3.2.8. The Audit Commission report (2003a) on Services for Disabled Children provides an excellent summary of current policy and legislation and should be referred to in association with this guidance.

The guidance in this book is intended to be used also in conjunction with *The Framework for the Assessment of Children in Need and their Families* (DH, DfEE, HO, 2000a). The Assessment Framework is another multi-agency endeavour which has been developed to 'provide a systematic way of analysing, understanding and recording what is happening to children and young people within their families and the wider context of the community in which they live' (preface, pviii).

In addition, a common assessment framework is currently being developed as part of the Green Paper, *Every Child Matters: Change for Children* (DH, 2003c) (see www.everychildmatters.gov.uk and Appendix B for policy details). Detailed guidance concerning how to undertake a multi-disciplinary assessment of a child and their family's needs is outlined in Sections 3.1.1 to 3.1.6.

1.3 Sharing best practice

The Department of Health supports and encourages the development of good working relationships, formation of clinical networks and sharing of best practice as key principles in the organisation and delivery of services. The outcomes for children and their families are most likely to be improved if individuals, NHS Trusts, local authorities, local education authorities, voluntary organisations and private sector companies all work together with a single common aim of improving both the quality and co-ordination of services.

Sharing best practice is particularly important for children requiring long-term ventilation as their numbers are still relatively low, and specific expertise and clinical experience is confined to a few specialist centres. As the numbers of children grow, many teams of professionals are finding that they are required to organise a discharge and deliver a package of support services for the first time. Rather than start from scratch, best practice should be shared within the NHS and by voluntary organisations, or private companies contracted to deliver services on behalf of the NHS. Sharing of best practice should include both the know-how and examples of clinical policies, procedures and documentation so that new services are developed to the same unified standard and the outcomes for children and their families are improved. The UK working party on children's long-term ventilation has established a website to share best practice and resources (www.longtermventilation.nhs.uk).

1.4 Parent and child involvement

The Department of Health and the Department for Education and Skills have recognised that children's views need to inform policy-making and practice (Lightfoot and Sloper, 2002). In a joint initiative launched in 2003, they have pledged to listen, hear and respond to children's views regarding their care and treatment (see Bibliography M for policy details). One of the key markers of good practice within Standard 8 of the NSF is that disabled children, young people and their families are routinely involved and supported in making informed decisions about their treatment, care and support, and in shaping services. Standard 2 of the NSF, Supporting Parenting, reinforces the importance of listening to parents' views. Detailed ways of involving parents and children in making decisions concerning all aspects of their care and education can be found throughout Section 3.

1.5 Risk management and clinical governance

Clinical governance is the framework through which NHS organisations are accountable for improving the quality of services and safeguarding high standards of care in order to create an environment in which clinical excellence can flourish (see also the NHS Clinical Governance Support Team website www.cgsupport.nhs.uk, and Bibliography D for links and references). The five themes of governance in this context are:

- clinical audit
- clinical effectiveness
- clinical risk management
- quality assurance, and
- staff and organisational development.

The clinical governance framework should be used to support and inform the development of quality services and pathways to support children requiring long-term ventilation.

Clinical audit

Standards of service delivery should be set and audit cycles used to keep reviewing and improving service delivery.

Clinical effectiveness

Where available, evidence should be used alongside collaboration with experts and joint working and sharing through dissemination. Work is in progress on agreeing national standards and pathways that should be locally applied as they develop (see www.longtermventilation.nhs.uk). It should be noted that this is a rapidly changing and evolving field as partnerships develop ways of managing this group of children who have such complex needs. There are other children who are not ventilated who have a corresponding need for complex care and it is important that developments and pathways link together in localities, informing each other, preventing duplication or gaps in service provision for individual children.

Fundamental to clinical effectiveness in this context will be the organisation and functioning of the multi-disciplinary team and shared governance arrangements that need to be developed. An additional consideration is the role of the voluntary and private sectors in delivering elements of care for this group of children and young people; there is a need for collaborations and shared governance arrangements that incorporate these sectors also.

Clinical risk management

Risk assessment and management plans are central to successful discharge and community care for these children and their families, and are applied across all sectors of provision. The process can often create unnecessary barriers to inclusion, flexibility and choice; this makes it difficult to achieve an ordinary childhood for these children. The concept of risk management needs to be considered at a number of levels and the principles applied to a number of areas embracing both clinical and environmental risk (see Section 3.1.19 and 3.2.8 for further practical guidance on these matters, and Bibliography D for supporting references). Children with complex needs require a progressive and innovative approach, in partnership with parents, aimed at enabling the achievement of ordinary childhoods for these children.

Quality assurance

Quality assurance structures should be built into any service development to facilitate monitoring and evaluation. It is important in this multi-agency context that this is undertaken from all perspectives: those of the child, family members, provider staff and other stakeholders. Attention to detail and robust systems and processes that ensure quality in all settings that the child may access is fundamental to ensuring appropriate and safe care delivery.

Staff and organisational development

Staff training, supervision and support are central to delivery of an appropriate workforce to meet the specialist needs of these children and young people. Competency-based training, support and supervision structures are extremely challenging as the team consists of both professional and non-professional staff. The care is also delivered in a variety of places, primarily in the family home. This means that more traditional ways of providing training and support within one environment are not easily available. There is an additional need to include multi-agency training to raise awareness of primary and secondary care personnel who may need skills assessment and development in order to meet the needs of these children. Implicit in this is ensuring a culture of child-focused care embracing the family system as the context for this. The clinical and practical implications of staff training and supervision are discussed throughout Section 3.

1.6 Safeguarding children

The exemplar containing the care pathway and supporting guidance (see Sections 2 and 3) is intended to provide a national framework within which agencies and professionals at local level individually and jointly draw up and agree upon their own more detailed ways of working together. The guidance should also be read in conjunction with *Working Together to Safeguard Children* (DH, 1999b) which sets national standards and procedures on inter-agency child protection work with the expectation that local areas will then construct their own procedures under the auspices of Local Children's Safeguarding Boards based on these national guidelines. Standard 5 of the NSF for children provides more information on the responsibilities of multi-agency partners with regard to safeguarding children. Specific information for Local Children's Safeguarding Boards in relation to protecting disabled children will be issued in April 2006.

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United Nations (1989) *United Nations Convention on the Rights of the Child. Including: Background to the Convention and Full Text of the Convention*. Children's Rights Development Unit, London. (See also www.unicef.org/crc/crc.htm)

Section 2

Exemplar care pathway for discharge management and community support

2.0 Introduction

This section contains an exemplar outlining the care pathway for the long-term ventilated child or young person. The care pathway for the child or young person requiring long-term ventilation has three stages:

1. the discharge process
2. living at home
3. growing up and transition.

The care pathway should be read in conjunction with both Section 3 (Hints, tips and tools for applying the care pathway locally), and the Bibliographies of resources. In addition, reference should be made to the UK Children on Long-Term Ventilation website (www.longtermventilation.nhs.uk) which aims to share information and contains an electronic document store from which many of the documents referenced in the Bibliographies can be downloaded and adapted for local use.

Rachel's journey through care

Rachel was born at term in good physical condition (normal Apgar scores) in the local hospital. After four hours, Rachel's mother Anna noticed that the baby looked grey and appeared to have stopped breathing. She was resuscitated and transferred to the neonatal intensive care unit for assisted ventilation and observation. Rachel was diagnosed at one month of age with Congenital Central Hypoventilation Syndrome (CCHS). This condition is sometimes referred to inappropriately as Ondine's Curse. She was subsequently transferred to the children's intensive care unit within the same hospital for further medical management and preparation for discharge home.

Anna is 20 years old and currently on maternity leave. She works as a clerical officer. Her partner David (Rachel's dad) is a shift worker. They have one other child – Peter, aged 2 years. They rent their current house from a housing association, and the house is in a rural area 10 miles from the hospital; they own a small family car. David's family live out of the area, while Anna's parents live locally but are both in full-time employment.

2.1 The discharge process

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Diagnosis and stabilisation</p>	<p>Rachel remains in the neonatal intensive care unit for several weeks while extensive investigations are undertaken to determine the reason for her dependence on the ventilator.</p> <p>Because of the length of Rachel's stay Anna is discharged home after one week, so she can carry on caring for their 2-year-old son, Peter. Anna and David visit Rachel every day and participate in her care as much as possible. The nursing staff help Anna to introduce Peter to the play staff so Anna is able to spend more time caring for Rachel during these visits.</p> <p>The consultant neonatologist and named neonatal nurse meet with Anna and David regularly, so that both feel well informed about what is happening. The hospital social worker also meets with Anna regularly to offer support.</p> <p>At the age of 1 month, Rachel is diagnosed as having Congenital Central Hypoventilation Syndrome (CCHS). The neonatologist communicates the diagnosis to the parents using the 'Right from the Start Template'. The information is given in a sensitive and empathetic way, recognising how difficult it is for Anna and David to have this diagnosis confirmed. The neonatologist understands the need for them to have sufficient time for the consultation. Anna and David also need time with the hospital social worker and nursing staff to talk and clarify their understanding. With Anna and David's permission, Rachel is referred to a children's respiratory consultant within the same hospital.</p>	<p>Standard 7 – appropriate hospital care</p> <p>Standards 1 and 3 – timely access to treatment and high-quality child- and family-focused care</p> <p>Standards 6 and 7 – access to appropriate care and staff trained in the care of children, and specialist care available as appropriate to the needs of young children</p> <p>Standards 2 and 3 – parents receive information and support to enable them to care for their child</p> <p>See Bibliography A for definitions, key policy documents and service specifications</p> <p>See Bibliographies H and J for references concerning 'breaking bad news', CCHS, other treatment modalities</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Transfer of care to the respiratory consultant and children's intensive care unit</p> <p>The neonatologist, respiratory consultant and named neonatal nurse meet with Anna and David to discuss the diagnosis and future plans. The respiratory consultant informs Anna and David that Rachel appears to be at the more severe end of the CCHS spectrum and is therefore likely to need mechanical ventilation for periods of the day, as well as overnight, for the rest of her life.</p> <p>The respiratory consultant recommends that Rachel has a tracheostomy formed as this will make the process of ventilation for Rachel much easier. With Anna and David's consent, Rachel is transferred to the children's intensive care unit for ongoing medical management and preparation for discharge home. Rachel is also referred to an Ear, Nose and Throat Consultant who arranges to form a tracheostomy.</p> <p>Anna and David are given written information about this condition and the implications it may have for both Rachel and her family. Information is also given on Contact-a-Family, so they can find out more about relevant support and groups that provide additional information.</p> <p>Rachel will spend several months in the children's intensive care unit. The nurses use their expertise to assess the developmental and support needs of Rachel and her family and ensure that her plan of care reflects these needs.</p>	<p>Standard 6 – timely and appropriate advice and services</p> <p>Standards 6, 7 and 8 – early intervention to aid recovery and rehabilitation</p> <p>Standard 2 – parents receive appropriate information</p>	<p>See Bibliographies J and M for guidance on involving children and their families</p> <p>Contact a Family helpline 0808 808 3555 CCHS family support e:mail: cchssupp@hotmail.com</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Referral to community nursing team</p> <p>The respiratory consultant anticipates at an early stage that community nursing services will be required to facilitate Rachel's discharge and manage her ongoing care. Anna and David give permission for Rachel to be referred to the community nursing team that has specialist knowledge and experience of discharging and caring for children receiving long-term ventilation (LTV) in the community. Following referral, the community nursing team identifies a 'key worker' who will be responsible for co-ordinating Rachel's discharge and ongoing care management.</p>	<p>Standard 6 – timely and appropriate advice and services</p> <p>Standard 8 – key worker to co-ordinate care</p>	<p>See Sections 3.1.7 and 3.1.8, and Bibliography E on the policy and practice of key and multi-agency working</p>
<p>Meeting the community nursing team</p> <p>The key worker who is a nurse from the children's community team, arranges with the family, and named children's intensive nurse, a time to meet and discuss in more detail the implications of LTV in the community. At this informal meeting Anna and David are able to ask lots of questions about what will be involved. The key worker gives the parents lots of information about the process and leaves them with some written information including a parent-focused preparation pack for children requiring LTV and a booklet that includes a variety of scenarios of the experiences of living at home with a child with long-term care needs.</p> <p>The key worker also introduces Anna and David to the Early Support Programme and takes them through the Family Pack, discussing with them ways this may be used to assist them as they learn to care for Rachel and work with the variety of professionals and agencies.</p> <p>Anna's mother also attends a follow-up informal meeting where she is given the opportunity to ask questions. Rachel's grandmother provides Anna and David with some support and has some questions of her own.</p>	<p>Standard 8 – co-ordinated family-centred services</p> <p>Standard 6 – children's community teams</p> <p>Standard 2 – receiving information</p>	<p>See Bibliographies J and M for source material on involving children and families</p> <p>www.earlysupport.org.uk</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Thinking ahead about funding and obtaining a preliminary funding agreement</p> <p>Anna and David are now aware that it will be necessary to involve professionals from other agencies to ensure that Rachel's needs are met in the most appropriate way. The key worker arranges a date for the first multi-disciplinary team meeting at a time when Anna and David can attend.</p> <p>The key worker recognises that it is obvious from the outset that Rachel's requirement will be for a level of provision above the core service provided for children, so the key worker undertakes to flag this need to the Primary Care Trust and local authority commissioners. This provides an early warning that a fully costed multi-agency care package proposal will be sent to them in writing within two weeks of the assessment of Rachel's needs being undertaken. The key worker also flags the need for the funding to be agreed in principle at an early stage. In Anna and David's area, plans are being developed for pooled budgets but these are not yet concluded.</p> <p>Anna and David are informed that funding will be applied for following the formal assessment of need, but told that they do not need to be concerned by this process and it will not delay the discharge plans.</p>	<p>Standard 8 – multi-agency packages of care</p> <p>Standard 8 – supporting complex needs</p> <p>Standard 8 – key worker to co-ordinate care</p>	<p>See Sections 3.1.3–3.1.6 for information and advice concerning obtaining funding, and Bibliography L on economic issues</p>
<p>Trialling equipment suitable for home use</p> <p>Anna and David are informed that specialist equipment for Rachel's long-term ventilation needs to be purchased. The children's respiratory consultant and key worker will work with company representatives to trial equipment that would be suitable for home use. It is important to find equipment that meets her ventilatory requirements, and is portable and easy to use in the community. The expertise of the specialist community nursing home care team streamlines this process. Rachel's other equipment needs (such as a pram to carry her equipment, appropriate bedding, etc) are assessed and documented by the key worker, occupational therapist and physiotherapist.</p>	<p>Standard 2 – parents enabled to have equipment and skills to ensure optimum life chances for children</p>	<p>See Sections 3.1.13 and 3.1.14 for information and advice concerning equipment, and Bibliography G on equipment and adaptations</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Thinking ahead about housing</p> <p>As issues around housing can take a long time to resolve, while trialling Rachel's equipment and thinking about her likely care needs, Anna and David and her key worker start considering the suitability of their home which is rented from a housing association. Anna and David fear that their two-bedroom house will not be big enough.</p> <p>The key worker anticipates the issue of the suitability of the family home at an early stage and refers them to a children's occupational therapist for an assessment of their housing which will be undertaken as part of the multi-disciplinary assessment of need (see 'Assessment' below).</p>	<p>Standard 8 – key worker to co-ordinate care</p>	<p>See Section 3.1.15 and Bibliography G for advice, source material and links concerning housing</p>
<p>First multi-disciplinary/ multi-agency meeting</p> <p>Before the meeting, the key worker encourages Anna and David to write a list of any questions they want to ask at the meeting. By the time of the multi-disciplinary meeting, they have already had the opportunity to meet a number of professionals from a variety of agencies and disciplines. At the meeting Anna and David indicate that they now have a much more realistic idea of what is going to be involved in caring for Rachel at home. They state that they feel able to take on the care required if given appropriate support. All professionals at the meeting also agree this would be the best course of action for Rachel.</p>	<p>Standards 1 and 8 – co-ordination and planning; access to targeted services</p> <p>Standards 6 and 3 – taking account of the family's unique needs and their views</p>	<p>See Sections 3.1.1–3.1.11 on planning the discharge process, and Bibliography B for source material and useful links</p> <p>See in particular Section 3.1.11 on managing a multi-agency meeting</p>
<p>Initial impressions of the extent of Rachel's needs are discussed, as are how the family members perceive they will meet these needs, including any gaps that they feel they will need help with. Key areas of consideration are that: Rachel is a second child and her sibling is at a pre-school stage; there is a lack of space in the house; and David's shift patterns will mean he is not available for regular hours to help.</p>	<p>Standard 8 – multi-agency planning</p>	

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Anna has already stated her intention not to return to work but this will create financial pressures for the family. Rachel's condition is severe and she will require ventilation both during the day and at night for the foreseeable future. This will mean she will have to have someone trained in caring for her tracheostomy and able to attach her to her ventilator; recognise the signs of deterioration and be able to respond by following protocols, and provide care for her while she is being ventilated, as well as when she is not ventilated. It was agreed that this person does not always need to be a qualified nurse but that, following training by a healthcare professional, unqualified carers, Anna and David and other willing family members could take on this role.</p> <p>At the meeting, the role of the 'key worker' from the community nursing team, concerning Rachel's discharge and home-based care, is clarified with all parties involved. The key worker will be the main link between Anna and David and other professionals who may need to be involved. Ways of working together are identified and agreed. A regular series of meetings with a small core group of professionals is arranged with the family, with a remit to progress the discharge plans and to support the key worker's role.</p> <p>Permission is given by Anna and David for information to be shared confidentially between different professionals to minimise duplication and repetition. Anna's mother attends the meeting to give Anna and David support, she also has some questions of her own.</p>	<p>Standards 6 and 1 – co-ordinated programme of action; long-term care</p> <p>Standards 6 and 8 – information-sharing and integration of services</p>	

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Assessment</p> <p>The assessment continues with the key worker leading the process. The formal assessment covers Rachel's care needs, the family's needs, taking due regard for Anna and David's views, as well as Peter's needs. It also covers a housing assessment carried out in partnership with the family, social services occupational therapist and the key worker who provides specialist knowledge about the particular needs of long-term ventilated children.</p> <p>The Framework for the Assessment of Children in Need and their Families, is used as a basis for the assessment, with health professionals adding on a specialised assessment relating to Rachel's technological care needs.</p>	<p>Standards 8 and 1 – assessment and early identification of child and family needs for multi-agency packages of care; supporting complex needs</p>	<p>See Section 3.1.1 on assessment, and Bibliography B for source material and useful links on assessment</p>
<p>Housing assessment</p> <p>The family's two-bedroom home is assessed as being too small to accommodate Rachel's needs for space and equipment. She will need a bedroom of her own so that Peter is not disturbed by the carers and machinery that will be needed while she is asleep. The bedroom also needs to be large enough to accommodate a comfortable chair for her carer to sit in during the night, ideally placed away from her direct bedside but within listening distance so she can be attended to promptly.</p> <p>The house will also require enough electric sockets for all Rachel's equipment, space for her equipment in the family living area so Rachel can be fully integrated with her family, as well as some dry storage area for her supplies and spare equipment. Other factors that will need consideration include access to the house so that Anna and David, and the carers will be able to get the two children and equipment easily in and out of the house, as well as dealing with all the routine things required for two small children. Ideally the house will have an outdoor area or garden. All other principles and</p>	<p>Standard 8 – children have access to a range of appropriate services and help to enable them to be included in the community</p> <p>Standard 3 – quality and safety</p> <p>Standards 5 and 6 – comprehensive and integrated local services</p>	<p>See Section 3.1.15 for advice on housing, and Bibliography G for source material and useful links concerning housing</p>

Journey	Children's NSF theme (England)	Policies evidence, and links
<p>requirements relating to disabled children and housing need to be also applied to Rachel's case.</p> <p>With Anna and David's permission, the key worker asks the local authority social worker, who is aware of the family's needs, to contact the housing association that owns the family home and request that it finds suitable housing for the family as soon as possible. The social worker will keep the key worker informed of progress and maintain direct contact with Anna and David to ensure their views are accounted for.</p> <p>Risk management</p> <p>A key part of the assessment process is a risk assessment relating to all aspects of Rachel's care. This is a difficult concept for Anna and David to understand, so the implications, underlying principles and process are explained to them in full by the key worker, so they can feel fully informed and involved, but not unduly concerned by the process. They understand that the main concern is for the ultimate safety of Rachel once she is at home. Local practice is followed to complete and document the assessments that are made, and necessary control measures are planned and put in place.</p> <p>Review dates and ongoing plans for risk assessments are documented as new aspects of care for Rachel are implemented. The experience of the key worker and links she has with others who are specialists in this field of work help in ensuring a pragmatic and safe approach to the plans for Rachel's discharge and care at home.</p> <p>One of the initial risk assessments detail the control measures that are necessary to enable Rachel, Anna and David to leave the intensive-care environment for short periods, for the appropriate equipment and back-up including battery power to be ascertained and for the training and</p>	<p>Standard 3 – quality and safety of services</p>	<p>See Sections 3.1.19–3.1.21 for advice on assessing and managing risks, and Bibliography D for source material and links concerning risk management and clinical governance</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>level of competence of those accompanying her to be agreed and documented.</p> <p>Anna and David are reassured that the need to ensure Rachel's safety is balanced with trying to achieve an ordinary life for her and her family. Their concerns and views about how this could be achieved are listened to and discussed, as their contribution to the risk assessment is an essential part of the process in order to develop and maintain the objectives of safety and an ordinary childhood and family life. Anna and David contact the CCHS Family Support group and find some tips from other parents about how they have overcome specific issues. For example, they investigate the use of an intercom system between themselves and the carer at night, to ensure the carer can call for help if required without coming into their bedroom.</p> <p>Prepare and submit proposal for a preliminary funding agreement</p> <p>All elements of the assessment are documented after Anna and David agree them. The key worker and social worker work with Anna and David, using the information about Rachel's condition and her expected progress, to decide on what level of support they will need to enable them to care for Rachel at home. David is particularly anxious that Anna has enough help while he is out at work and they are both keen for Peter not to feel left out and to have time to be with him also.</p> <p>In making the decision about what type and amount of support they need, Anna and David find it helpful to have a range of options suggested to them that include the positive aspects as well as the challenges that they are likely to face. They agree on the need for a carer each night and additional support during the day.</p>	<p>Standard 8 – multi-agency planning</p> <p>Standard 3 – robust commissioning</p>	<p>See Sections 3.1.3–3.1.6 for information and advice concerning obtaining funding, and submitting a proposal, and Bibliography L on economic issues</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>The key worker undertakes the task of putting together the joint assessment and care-package proposal, having incorporated views from all the people involved in Rachel's care using locally agreed criteria for application for continuing healthcare and social services funding. This includes costs of employing care staff as well as key pieces of medical equipment, spares, disposable items and maintenance costs that will be required on a regular basis.</p> <p>The proposal is brought to the hospital and discussed at a meeting with Anna and David before a final draft is sent to the Primary Care Trust for funding to be agreed. The proposed care package is based on recruiting a team of non-professional carers to be trained specifically in Rachel's care. These carers will assist Anna and David in caring for Rachel in the home setting and other settings that Rachel may access as she grows up.</p> <p>The initial agreement is to provide a carer for the family for 9 hours every night and for 5 hours during the day on the days that David is out at work. The amount of short-break care will be flexible and agreed once the family is established at home but will be provided by the same team of carers, to ensure continuity for Rachel. Social services makes a financial contribution to funding the short-break aspect of the care package.</p> <p>An action plan is agreed at the end of the meeting with Anna and David, which is documented and includes specific actions and responsibilities for actions with timescales among those at the meeting. Wider sharing of these notes and plans is also negotiated. Anna and David are happy with the content of the proposal and do not wish any changes to be made. They are aware that there will be flexibility built into any package that is devised so minor changes can be made later.</p>		

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Funding agreed</p> <p>The key worker has already flagged up the need for an agreement in principle for funding with the Primary Care Trust, so it is expecting the proposal when it arrives.</p> <p>The proposal is then forwarded to the appropriate commissioners following local practice with a summary sheet and covering letter requesting that the decision regarding funding and future care provision be communicated to the key worker. The commissioners agree to the request for funding within one week. Now that the funding has been confirmed the key worker can begin to advertise for care staff.</p>		
<p>Training parents</p> <p>Rachel is now recovering from having a tracheostomy formed and is established on the equipment she will be using at home. The named children's intensive care nurse and the key worker work together to develop a training plan for Anna and David to follow to enable them to become confident and competent in all aspects of Rachel's care. Anna's mother also agrees to undertake this training so she can offer as much support to Anna as possible.</p> <p>The training programme is structured around Anna and David's availability to be at the hospital which is dependent on work and childcare commitments. Anna's mother and a family friend provide invaluable support by looking after Peter so that Anna and David can both visit Rachel on most days.</p> <p>The children's intensive care nurses and the play specialist work with Anna to begin to introduce some routine and developmental stimulation for Rachel into her daily care programme. The hospital social worker makes a referral to the local authority disabled children's social work team in the family's area.</p>	<p>Standard 2 – equip parents with the skills they need to ensure their children have the optimum life chances</p> <p>Standard 4 – age-appropriate services for all children</p> <p>Standard 7 – play for children in hospital</p> <p>Standard 2 – receive services to support and enable caring</p>	<p>See Section 3.1.18 for advice on training parents, and Bibliographies C and D for examples of packages and competencies</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>The key worker liaises with the social workers to ensure Anna and David are provided with useful financial advice, including information on disability related benefits, child and working tax credits, rights to parental leave and how to apply to the Family Fund. This is particularly important in view of Anna's decision not to go back to work.</p> <p>The social worker also helps Anna consider different options for childcare for Peter and arranges with the hospital play room for him to have some sessions there while Rachel is in hospital so he can continue his pre-school programme and be with Anna.</p> <p>A step-by-step approach is taken to Anna and David's training and they have a written record at all stages to support what they are being taught. A named children's intensive care nurse and the key worker oversee the training programme and have the role of assessing progress as well as the pace and timing of the programme. They also regularly check how Anna and David are feeling and negotiate a balance with them that means they do not feel pushed to take on tasks but gradually build up confidence in their own abilities to learn Rachel's specialised care. Gradually, Anna and David start caring for Rachel on their own for short periods of time, knowing at all times where and how to ask for help if they want or need it.</p>	<p>Standard 8 – flexible and sensitive care</p>	<p>www.familyfund.org.uk</p>
<p>Discharge plan</p> <p>The discharge plan is made following a framework for discharge planning that has been adapted locally. This includes timescales, actions and responsibilities. The key worker provides a discharge-planning checklist that is individualised for Rachel and her family; a copy is given to Anna and David so they can feel fully involved in the process and be confident that all aspects of Rachel's discharge are being addressed and be clear about who is responsible for them.</p>	<p>Standard 7 – discharge is planned in good time in liaison with relevant agencies and professionals</p>	<p>See Sections 3.1.9–3.1.11 for advice on managing the discharge process, and Bibliography B for source material and links concerning discharge management</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Agreement of care</p> <p>An agreement of care between the family and the community nursing service is drawn up and agreed with Anna and David. This is a useful tool to help establish a working partnership between the family and community nursing team, and to ensure clarification of roles, responsibilities and expectations.</p>	<p>Standard 3 – services co-ordinated around family needs and taking account of their views</p>	
<p>Recruitment and training of home carers</p> <p>Because the community nursing team already has ventilated children within its caseload, it is familiar with the recruitment and training process. Two trained but unqualified carers from the existing community nursing team identify themselves as wanting to become involved in Rachel's care and are introduced to Anna, David, Peter and Rachel on the children's intensive care unit. These carers have already undergone a robust training programme and are experienced in the care of children requiring LTV. They begin working with Rachel, initially with supervision, while the key worker works with the Human Resources department to advertise for more carers in order to fully support the family's package of care. Funding has been agreed for this and for the use of some trained staff from a bank of nurses to be used in the first stages of Rachel's time at home to support the carers' training programme at home.</p> <p>Anna and David are consulted about the recruitment process but not expected to be closely involved; they understand this is because the carers will also be working with other children in the community. They are confident that they will be able to meet and get to know newly recruited carers and be involved in their training and orientation programmes later on. Agreements are made between the community and children's intensive care nursing teams to allow community carers to start working with Rachel in hospital so they can become familiar with her individual needs prior to discharge. This is</p>	<p>Standard 3 – core competencies and skills to work with children and young people</p> <p>Standard 6 – high-quality care based on evidence-based guidelines and protocols</p> <p>Standard 3 – services listen and respond to the views of children and parents</p> <p>Standard 7 – supporting co-ordination of community-based care to keep hospital-based care to a minimum</p>	<p>See Sections 3.1.16–3.1.18 for a definition of a 'carer' and advice on the process of recruitment and training. See Bibliographies C and D for guidance and examples of job descriptions, training programmes and competencies</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p data-bbox="411 360 911 465">received well by Anna and David as they have the opportunity to get to know staff in a controlled environment.</p> <p data-bbox="411 501 927 678">Experienced carers are able to help resolve some of the practical problems that hospital staff may be unfamiliar with, such as how to load the ventilator onto the buggy for trips off the ward.</p> <p data-bbox="411 714 879 819">After an initial orientation period these carers are assessed as being competent to meet Rachel's needs.</p> <p data-bbox="225 855 339 920">Day trips home</p> <p data-bbox="411 855 927 1346">Anna, David and Anna's mum have now all completed the training programme and are confident in all aspects of Rachel's care. They have already started to take Rachel off the ward for short trips to the playroom with Peter. Anna is now very keen to take Rachel home but appreciates that it is still likely to be some weeks before the family is re-housed and sufficient carers are recruited and trained. In consultation with the key worker, it is agreed that the family can start taking Rachel home for the day and return each evening for overnight care in hospital.</p> <p data-bbox="411 1382 927 1800">For the first few trips home the key worker accompanies Anna to help iron out any unpredicted difficulties. David is able to alter his shifts to enable him to be present as often as possible. When no family member is available the children's intensive care unit is usually able to provide a member of staff to help Anna with the journey home. The day trips home have gone without any adverse incidents and Anna's confidence in her ability to manage both of her children is growing.</p>	<p data-bbox="956 855 1166 920">Standard 3 – safe care</p>	<p data-bbox="1209 855 1418 960">See Bibliography I for clinical protocols</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>New carers start work</p> <p>Two new carers have completed the recruitment process and are now ready to begin work. The key worker has developed the training package and tailored it to Rachel's needs. The new carers are introduced to the family and ward staff.</p> <p>Over the next few weeks they undergo both classroom-based learning and practical learning on the ward with hands-on experience of caring for Rachel while being supervised by qualified nurses. The key worker regularly checks on their progress.</p>	<p>Standard 3 – appropriately trained staff</p>	<p>See Sections 3.1.16–3.1.18 for a definition of a 'carer' and advice on the process of recruitment and training. See Bibliography C for human resources guidance and examples of job descriptions</p>
<p>Moving house</p> <p>A three-bedroom house has been offered to the family by the housing association. It is close to Anna's parents – so they accept the offer. When the family registers with a new GP practice, the key worker contacts the new local primary care team. The key worker follows up a telephone call with a letter introducing the family and suggesting an initial meeting. The same health visitor works with the new practice, which provides some continuity for the family.</p>	<p>Standards 6 and 8 – access to services and support through local arrangements and access to primary healthcare</p>	<p>See Bibliography G for source material and links concerning housing</p>
<p>Equipment at home</p> <p>All equipment and associated supplies are now in place at home; initially these were provided from the hospital but are now going to be ordered by the key worker, charged to Rachel's community budget and delivered to the local health centre which is convenient for Anna or David to collect from.</p> <p>Anna has organised Rachel's bedroom with plenty of storage space, space for care staff and room for Rachel to play. Anna and David are becoming both excited and anxious about Rachel's impending discharge. The key worker introduces Anna to another local mum whose child is receiving LTV. Although the children's needs are different, Anna finds this contact very reassuring.</p>	<p>Standard 8 – access to appropriate equipment</p>	<p>See Sections 3.1.13 and 3.1.14 on managing equipment and disposable supplies, and Bibliography G for source material and links</p>

	Journey	Children's NSF theme (England)	Policies, evidence, and links
Final discharge meeting	<p>All preparations are complete, so a final discharge meeting is arranged to check that everyone involved (Anna and David, professionals and carers) is still happy with the arrangements, and to tie up any loose ends.</p>	<p>Standard 7 – discharge is timely and staged to meet needs of family</p>	<p>See Section 3.1.1.1 on managing an effective discharge meeting</p>
The first night home	<p>A trial run is arranged for Rachel to stay at home overnight with a qualified children's community nurse and a trained carer providing the night-time cover. Anna and David are reassured that they have 24-hour access to speak to either medical or nursing staff from the children's intensive care unit, as well as the support and back-up from the community nursing team.</p> <p>This first night home goes well so it is agreed to discharge Rachel home into the care of Anna and David with support from the community nursing team.</p>	<p>Standard 2 – specialist services provide timely and appropriate support to enable parenting</p>	<p>See Section 3.1.2.1 on written procedures and protocols</p>
Final discharge arrangements	<p>A date and time for discharge are set in agreement with Anna and David. The emergency services and utility companies are informed by the key worker of the planned discharge date; they have already been contacted and agreements about priority services to the family home have been made.</p> <p>Letters are written following phone calls confirming all the plans for discharge and follow-up to the GP, primary care team and other professionals involved in delivery of Rachel's ongoing care. Arrangements for medication provision have already been made with both the GP and local pharmacy so that the process works well for the family.</p> <p>The hospital play specialists have worked with Anna and David in preparing Peter to have his sister at home, and to understand her special needs according to his age and stage of understanding and development.</p> <p>Rachel is discharged home.</p>	<p>Standard 8 – children with complex needs have increased access to services to support their needs</p> <p>Standard 7 – importance of play and preparation for all children</p>	<p>See Section 3.1.8, and Bibliographies E on key working and B for source material and links on discharge management</p>

2.2 Living at home

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Case management/ key working and multi-agency working</p> <p>Once home, Rachel receives a variety of services and resources from a number of different agencies as outlined in her care package. In order to facilitate good communication across all agencies and sectors, the team leader responsible for managing Rachel's community nursing team is designated as the key worker responsible for co-ordinating all aspects of the care package. In Rachel's case this is the same person who acted as her key worker to facilitate her discharge from hospital. The key worker continues to work in close partnership with Anna and David to enable them to take control of their family life and home as well as enabling them to have access to services at the appropriate time and be supported.</p> <p>Key working in domestic settings entails working with Rachel, Anna and David as partners in care, and includes activities such as:</p> <ul style="list-style-type: none"> • managing the daily organisation of the care package on behalf of Rachel and her parents • liaising with all other professionals and agencies to ensure smooth and co-ordinated delivery of services with minimal overlap, thus reducing the intrusion and disruption of inappropriate telephone calls and visitors to the house • providing ongoing emotional, psychological and developmental support for Rachel, Anna, David and Peter, other family members and employed staff • developing house rules with Anna and David to ensure that professionals and parents understand each other's needs and ways of working • developing and implementing policies and procedures to ensure the safety of everyone in the home (health and safety, risk management, child protection) • organising the maintenance/replacement of equipment 	<p>Standard 8 – key worker to co-ordinate care; child-centred approach, family/holistic context</p> <p>Standards 2 and 8 – the child and family receive services and support to ensure optimum life chances and inclusion</p> <p>Standard 6 – high-quality care for children with long-term conditions and their families</p>	<p>See Sections 3.1.8, 3.2.1–3.2.5 for advice concerning the role of the key worker at home, and Bibliography E for sources and links on key and multi-agency working</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<ul style="list-style-type: none"> • ordering disposable equipment and supplies • organising medicines and other pharmacy products • helping Anna and David to co-ordinate hospital, clinic and therapy appointments and ensure minimal overlap • facilitating an annual reassessment of the care package (more frequent if necessary) to ensure that as Rachel grows up her care package is flexible and responsive to her changing needs. <p>Anna and David begin over time to build relationships with members of the multi-disciplinary community support team around Rachel. The core team of professionals works with them to pay attention to both Rachel's health, social and developmental needs and their own needs as individuals and a family unit, in particular their emotional needs and desire for an ordinary family life.</p> <p>Initially the family is delighted to be at home and everything seems to run very smoothly; Anna and David feel confident in their training and the abilities of the professionals and carers who are supporting them. However, after about 6 months, Anna wonders why she is feeling a bit low and finding it difficult to be tolerant of some members of care staff. In discussions with the key worker and other parents she is in contact with through the CCHS Family Support Group, she comes to realise that this is a normal reaction once the euphoria of getting Rachel home has passed and the reality of caring for Rachel and Peter becomes clear. Anna is made aware of the availability of counselling and psychology services if she should feel this may be helpful at any time.</p> <p>The key worker visits the family home regularly, negotiating the times with Anna</p>	<p>Standard 8 – flexible and sensitive care</p> <p>Standards 3 and 8 – services listen and respond to families and are co-ordinated around their needs</p>	<p>See Sections 3.2.3 and 3.2.5 concerning the impact on family life, and Bibliography H for source material and links concerning the roles of parents in domestic settings</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>for her convenience, and has telephone contact with the family in between. This ensures that Anna and David are kept fully informed about all actions being taken by the key worker. They appreciate knowing both about actions that are being progressed as well as areas where progress is very slow. They feel fully involved and informed while not having to take on the stress of chasing up services. The key worker's honesty, openness and clarity are respected by Anna and David who feel this supports them in developing an effective and supportive relationship with their care team. In turn they undertake also to try and communicate with the care team in a constructive way.</p> <p>Ongoing recruitment and retention of carers</p> <p>One of Rachel's employed carers gives four weeks notice of leaving to take up a new post elsewhere. The key worker ascertains that the carer felt bored and deskilled working at night with a child who mostly slept through the night. Other carers express similar sentiments. The key worker actively initiates a number of steps to improve the job satisfaction and stimulation of carers, including opportunities to:</p> <ul style="list-style-type: none"> • work with other families in the community • update their competencies • rotate to the local NHS Trust to update/enhance skills • undertake distance learning modules at night, and • attend relevant conferences and professional updates. <p>In addition, the key worker facilitates a recruitment campaign to ensure that Rachel's care team is as described in the care package. In the interim, an agency/ bank nurse is employed, trained and assessed to work within Rachel's team.</p>	<p>Standard 8 – key worker co-ordinates care</p>	<p>See Bibliography C for source material and links concerning human resources</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Short breaks and holidays</p>	<p>Rachel's care package contains some additional flexible hours so that Anna and David can engage in their own educational or social activities. One of the carers who knows Rachel well and in whom Anna and David have confidence, is assessed as competent to provide this respite care during the evening. Anna and David work with the key worker to ensure that this goes smoothly. Anna's mother comes to look after Peter and provide some back-up for the carer.</p> <p>Towards the end of her first year at home Anna and David want to go on holiday to a hotel in another part of the country for a week. They discuss this with the key worker and a plan is worked out to make all the necessary arrangements. The commissioners are contacted and it is agreed that a carer can accompany the family on holiday, so that the family can have some rest also. A carer agrees to go with the family for four nights; Anna and David will cover the other nights' care themselves, with the help of Anna's parents. The family applies to the Family Fund to pay for the carer's separate accommodation and the carer has a subsistence allowance for food. This arrangement is achieved through careful negotiation with the family to ensure that there is clarity about roles and responsibilities for the carer, and to ensure Rachel's safety in an unfamiliar environment.</p> <p>Before the family goes on holiday, the key worker liaises with the community children's nursing service in the locality of the hotel to ensure that they are aware of Rachel's needs, and provide Anna and David with a contact point for help if they should need it while they are there. Rachel's consultant also makes contact with a lead consultant at the local hospital to provide appropriate back-up.</p>	<p>Standards 8 and 2 – services are organised around the needs of the family and support and enable them to care and parent their children</p> <p>Standard 3 – services work with families to ensure high-quality care and take account of their views</p> <p>Standards 6 and 8 – families supported in the self-care of their illness and have access to appropriate services</p> <p>See Section 3.2.7, and Bibliography M for advice and source material on play, leisure, short breaks and family support</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Medical reassessment and follow-up</p> <p>Rachel is regularly reassessed at a multi-disciplinary clinic specifically for children on long-term ventilation, with a staff including:</p> <ul style="list-style-type: none"> • a children's respiratory consultant • a community paediatrician • a children's speech therapist • a children's dietician • a social worker • a children's occupational therapist. <p>This clinic provides Anna and David with an opportunity to discuss all aspects of Rachel's care with the relevant people at one appointment, which they find invaluable. It helps those delivering her care to ensure a consistent approach that meets with the family's wishes and needs.</p> <p>Rachel continues to see the speech therapist on a regular basis as she learns to talk with her tracheostomy. Anna and David and her carers are trained by the speech therapist to assist Rachel in the required techniques for communicating on a daily basis.</p> <p>Rachel also requires regular sleep studies either at the hospital sleep lab or at home. Her carers, and Anna and David, are trained to use the monitoring equipment at home to prevent her having to attend hospital. However, not all the investigations can be done at home and when Rachel needs to go for a routine sleep study in hospital, arrangements are made for her carers to accompany her so that she receives continuity of care and to minimise the effects of the hospital admission on her.</p>	<p>Standard 8 – children with complex needs receive co-ordinated family-centred services</p> <p>Standard 2 parents receive information and support</p>	<p>A protocol for the follow-up and ongoing monitoring of ventilated children written by Professor Peter Fleming can be found in Bibliography J</p>
<p>Emergency readmission to hospital</p> <p>Rachel has a protocol in place in case of the need for emergency readmission to hospital. Twice during her first year at home, Rachel requires readmission to hospital with an acute chest infection. The agreed protocol enables Anna and David and the key worker to seek advice early from the GP and subsequently from the respiratory consultant at the regional hospital. Rachel is transferred by paramedic</p>	<p>Standard 7 – children receive care in hospital that is integrated and co-ordinated and delivered in an appropriate setting</p>	<p>See Section 3.2.6 for advice concerning returning to hospital</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>ambulance to hospital before her condition deteriorates too far.</p> <p>Anna and David have a parent-held record that summarises the key points regarding Rachel's diagnosis and treatment plan.</p> <p>Each time Rachel is readmitted to the children's intensive care unit, she has an acute respiratory infection, which means she becomes medically unstable, and beyond the scope of her home carers' skills. On admission to hospital her care is transferred to the intensive care unit qualified nursing and medical staff. Her care team is redeployed to work with other children and families and some carers take annual leave. Anna and David miss the familiarity of the carers who know Rachel, but understand that the level of care they would be able to provide would not meet Rachel's current acute care needs.</p> <p>As Rachel begins to recover, a few members of her care team arrange to visit Rachel in liaison with Anna and David and the key worker. When Rachel is recovered from her acute chest infection and is considered to be medically stable, she is once again discharged home to the care of Anna and David and her home-care team. Her discharge is organised by her key worker.</p>	<p>Standard 1 – parent-held child record</p>	
<p>Multi-agency care plan reviews</p> <p>Rachel and her family's practical and support needs are continually reassessed and evaluated in partnership with them in recognition of their need for varying levels of care and support at different times during Rachel's life. For example, when Rachel's grandmother becomes unwell for a period of time and is unable to help Anna with her weekly shopping trip, it is agreed that the family can have extra short-break care hours, to enable David and Anna to do the shopping together without having to worry about the children. Once Anna's mother is better, the original arrangements are re-established.</p>	<p>Standards 8 and 4 – children and families receive ongoing appropriate support and age-appropriate services to meet their specific needs as they grow up</p>	<p>See Section 3.1.7 and Bibliography E for source material and useful links on multi-disciplinary working</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Rachel's multi-agency care plan reflects services working together to accommodate the peaks and troughs experienced by the family. It is a working document that is shared and details all the professionals and services that are required. It ensures access to services that are timely, appropriate information about services, and reassurance for Anna and David that their needs have been understood and considered.</p> <p>A proactive approach to Rachel's care, and reviews at regular intervals, ensures that both Rachel's stability and other factors impacting on the family's ability to cope and manage differing thresholds are considered and planned for as well as possible.</p> <p>Education</p> <p>Nursery By age three, Anna and David feel that she is ready and would benefit from attending a nursery school in order to meet more children of her own age. Rachel begins to attend a local authority nursery school once agreement is reached between the local education authority, nursery and health service commissioners about the provision of appropriate support being available to meet Rachel's needs within the pre-school setting.</p> <p>Initially, Rachel attends nursery for two mornings a week; this increases to three full days over time. In order to accommodate her increasing need for daytime care while at nursery, her care package is adjusted to provide a carer to cover her nursery hours and transport time to and from nursery.</p> <p>Rachel's key worker liaises with the nursery to provide information for staff regarding Rachel's needs and helps the nursery manager to undertake an assessment of risk using the principles of risk assessment applied to all aspects of Rachel's life. A healthcare plan is developed by the key worker in partnership with Anna and David to provide details of the care she will</p>	<p>Standards 8 and 4 – children and families receive ongoing appropriate support and age-appropriate services to meet their specific needs as they grow up</p> <p>Standard 9 – partnership working for children with psychological and special educational needs</p> <p>Standards 3 and 8 – integration between education/social and health needs; sharing of information, continuity and co-ordination of care</p>	<p>See Section 3.2.8 and Bibliographies A and F for key policy documents and best-practice guidance concerning supporting Rachel through early years and school</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>require in nursery. This is used as the basis for training the nursery staff and her carers. As the key worker is a healthcare professional, they are able to fulfil both these roles to facilitate Rachel's pre-school attendance, with the full co-operation of the nursery staff.</p> <p>As Rachel requires a mid-morning or mid-afternoon sleep, and therefore ventilation, and she is still not old enough to care for her tracheostomy safely, it is agreed by the nursery and all agencies involved that the home carers who already know Rachel well will be funded to accompany Rachel to nursery. An honorary contract, which addresses insurance concerns, is agreed with the carers. Anna and David feel pleased and confident with this arrangement that will provide continuity and the appropriate level of expertise for Rachel's care to be delivered safely. She takes her own equipment into nursery with her on a daily basis and a trolley is made to assist with access to the nursery and for movement around the building.</p> <p>The nursery will provide training for the carers relevant to the setting to enable them to support Rachel appropriately with her learning. Emphasis is put on integrating Rachel into the nursery setting and arrangements made to allow her 'space' away from the carers, but so that they can observe her and ensure she receives appropriate medical help if and when she needs it.</p> <p>The key worker gives an information and awareness session about Rachel's needs to the nursery staff so that they can be supportive of the approach required for her care. The risk assessment has identified a need for designated staff to be trained in first aid and emergency resuscitation techniques and the key worker works with the nursery manager to identify appropriate staff to deliver this training, and staff to attend the sessions.</p>	<p>Standard 8 – children with complex needs are fully included and enabled to lead ordinary lives</p>	

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Primary school At age five, Rachel starts primary school full-time. Careful multi-agency planning and risk assessment is undertaken with the key worker taking a leading role to ensure the smooth transition of Rachel into school. A ventilator is not required as Rachel no longer requires ventilation during the day. Her care package is gradually reduced as a member of the school support staff already contracted to provide support for children with health needs takes over from her own carers whilst at school. A plan is put in place for the assistant to gradually learn about her care and eventually support Rachel and another child in the same class.</p> <p>The assistant is trained to care for Rachel's tracheostomy and in all emergency procedures. Initially Rachel's carers who accompanied her to nursery work alongside the assistant as they gain confidence and competence in performing Rachel's care. Once the support assistant is assessed as competent by the key worker, the carers move on to work with another child although they remain in contact with Rachel as they do some night-time care for the family.</p> <p>Rachel progresses well in school and continues to have joint reviews of her education, health and social care needs. Her healthcare plan is updated regularly as her needs change and she becomes more independent. She adjusts well to life in school and integrates well with her peers who both support Rachel and accept her additional support needs.</p> <p>Secondary school At age 11 years Rachel transfers to her local secondary school. The principles of risk assessment are applied again and support assistants identified for training, although their role is now more supportive of Rachel in delivering her own care for her tracheostomy. In Rachel's area the majority of the children who she</p>		

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p data-bbox="225 577 355 678">Change to mask ventilation</p> <p data-bbox="413 365 925 539">knows from primary school will be attending the same secondary school as her. This helps Rachel as she feels she is in familiar company, even though teaching and support staff, and other routines differ.</p> <p data-bbox="413 577 911 819">Rachel, Anna and David, and her children's respiratory consultant talk about a planned changeover from tracheostomy to mask ventilation. Rachel is keen for her tracheostomy to be closed so that she can be more independent, and plans for this are started.</p>	<p data-bbox="952 577 1185 786">Standards 3 and 8 – integrated co-ordinated care, which is flexible to changing needs and circumstances</p> <p data-bbox="952 824 1185 965">Standard 4 – respecting and involving young people in their care</p>	<p data-bbox="1206 577 1382 714">See link to the Expert Patient Programme in Bibliography M</p>

2.3 Growing up and transition

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Adapting the care package over time</p>	<p>As Rachel grows up, her care package requires adaptations as her needs change. Her key worker organises an annual reassessment that involves Rachel, Anna and David, and relevant service managers. The minutes of meetings and an agreed plan of action are circulated to Rachel, Anna and David, and all relevant agencies.</p>	<p>Standards 3 and 8 – integrated co-ordinated care, which is flexible to changing needs and circumstances</p>
<p>Developing self-care strategies and independence</p>	<p>As Rachel matures, she increasingly asks to see professionals by herself as she wants to become more independent. Anna and David find this transition difficult at times as they feel they are beginning to lose control over Rachel's care, although they recognise the importance of her taking responsibility for her own health needs.</p> <p>The change to mask ventilation has made a big difference to Rachel's life and she grows in confidence and enjoys her independence. Rachel wants increasingly to go out and enjoy varied social opportunities with her friends. Risk-management policies are adapted as Rachel matures and wants more independence, and to go out more at night. The roles of her carers are adjusted so that Rachel can attend social activities such as clubs and live music events. The key worker provides Rachel (and Anna and David) with important health promotion advice about the specific increased dangers to her health of smoking and illegal drug use.</p> <p>As Rachel is highly dependent on ventilation, she still requires some assistance from carers at night – but their hours are reduced in line with Rachel's wishes. In addition, Rachel says that she no longer wants her carers to sit in her bedroom at night. Discussions are initiated with the housing association and the local authority housing department about Rachel's future housing needs. Ideally Rachel would like a separate room for her carers with an</p>	<p>Standard 4 – respecting and involving young people in their care; flexibility of services as young people develop into adulthood</p> <p>Standard 8 – promote inclusion of disabled children and young people</p> <p>See link to the Expert Patient Programme in Bibliography M</p>

	Journey	Children's NSF theme (England)	Policies, evidence, and links
Transitions through education	<p>interconnecting door to her room to allow her some privacy.</p> <p>Rachel achieves good examination grades at school and, as she approaches the age of 16 years, she discusses with her parents and careers advisor at school the options for her future education. Rachel decides that she would like to go to university after completing her A levels. Rachel wants to go to a local university so that she does not have to leave home or change her carers with whom she has a good relationship. Rachel, Anna and David contact the local university disability support office and an advisor helps Rachel to submit her application and identify her support needs at university.</p>	<p>Standard 3 – integration between education/social and health needs</p> <p>Standard 4 – growing up, young person increasingly involved in decisions</p>	<p>See Bibliography F for guidance on supporting young people through education</p>
Direct payments and welfare payments	<p>Rachel's social worker explains that she may be able to receive Direct Payments rather than services for her support needs from the age of 16 years. Rachel is provided with a video to take home which explains the advantages and disadvantages of the Direct Payment scheme.</p> <p>Rachel will also be able to access different welfare payments as she passes certain birthdays and depending on whether she is still in full-time education. Her social worker advises her, directing her to the Department of Work and Pensions website for additional information on welfare payments, and provides assistance as needed in identifying options.</p>		<p>See Bibliography L for guidance on Direct Payments</p> <p>www.dwp.gov.uk</p>
Transition to adult services	<p>Until now Rachel has been cared for by a specialist children's long-term ventilation service and a team of community children's nurses. When Rachel is 15, the children's respiratory consultant suggests that it may now be the right time to think about transferring her care to a local adult service. The process of transition is planned carefully by the respiratory consultant and key worker along with Rachel and her parents so that at age 16 years she transfers to adult services.</p>	<p>Standard 4 – smooth transition to adult services</p> <p>Standard 8 – transition into adulthood</p>	<p>See Sections 3.3 and 3.4, and Bibliography K for best-practice guidance and literature concerning transition</p>

Section 3

Hints, tips and tools for applying the care pathway locally

Contents of Section 3

3.0	Introduction	42
3.1	Planning for discharge of a child from hospital	42
3.1.1	Undertaking a multi-disciplinary assessment of the child's needs	42
3.1.2	Assessing the needs of parents	44
3.1.3	Identifying an appropriate model of service provision	44
3.1.4	Obtaining agreement to fund a package of care	44
3.1.5	Calculating the cost of the care package	47
3.1.6	Direct Payment scheme	53
3.1.7	Getting multi-disciplinary, multi-agency, cross-sector service providers working together as a team	53
	The multi-disciplinary, multi-agency, cross-sector team	54
3.1.8	Bringing about effective key working	55
3.1.9	Managing the discharge process	56
3.1.10	Discharge checklists	57
3.1.11	Managing a discharge meeting	62
	Organising the meeting	62
	Managing the meeting	63
	Actions following the meeting	63
3.1.12	The parents' role	63
3.1.13	Purchasing and maintaining equipment for long-term ventilated children	65
	Community equipment	65
	Technological equipment	66
	The equipment required by Rachel	68
3.1.14	Disposable equipment and supplies	69
3.1.15	Adaptations to housing	70
3.1.16	Defining the term 'carer'	71
3.1.17	The process of recruiting carers	72
	Strategies to aid recruitment and retention of carers	72
3.1.18	Training and competencies of parents, carers and nurses	73
3.1.19	Assessing and managing risks	74
	Risk assessment	75
3.1.20	Attitude to risk of the child and family	82
3.1.21	Written procedures and protocols	84

3.2	Delivering care in domestic settings	85
3.2.1	Health and safety in domestic settings	85
	Hand washing and hygiene in domestic settings	85
3.2.2	Key working once the child is home	87
3.2.3	The home as a workplace	88
3.2.4	The role of carers in relation to the family	89
	Who trains the carers?	90
3.2.5	Impact on family life	90
3.2.6	Returning to hospital	91
	Routine admissions	91
	Emergency admissions	92
	Unplanned admissions	92
3.2.7	Play, leisure, short breaks and family support	93
3.2.8	Starting or returning to school	94
3.3	The young person's changing social needs and sexuality	97
3.4	Transition to adult services	98
3.5	Implementing cross-department national policies to improve outcomes for children with complex needs	98
	References	101

3.0 Introduction

England, Scotland, Wales and Northern Ireland have specific institutional structures, health and social policy, and services that reflect the needs of their respective populations. It is important that this guidance is used as a resource alongside local policy and practice, and is adapted where necessary to reflect local organisation and service delivery. Examples of best practice have been received from all countries that make up the United Kingdom and the underlying principles are applicable to all aspects of care irrespective of where it is delivered.

The child featured in the care pathway in Section 2 has a diagnosis of CCHS and associated complex needs for health and social care. Although specific medical management and the requirement for personalised packages of services and resources will need to be tailored to individual children and their families, the principles concerning discharge and ongoing care management apply equally to children of differing ages, diagnoses and associated impairments who require long-term ventilation.

Irrespective of the locality, age, diagnosis or impairments of the child, the aim of any integrated pathway is to link children and families with community services, hospital-based services, social services, education and the voluntary sector in a joined-up planning and service delivery process (Limbrick, 2003; ACT, 2004). Pathways provide an accepted framework against which services can set goals and measure quality to ensure continuous service improvement (see National Pathways Association, www.the-npa.org.uk). The use of a pathway approach within this guidance is in line with a key recommendation of the NSF for children's services to use pathways and journeys to ensure the child is the focus of service delivery and to prevent discontinuity.

The following subsections provide practical advice and guidance on implementing the care pathway locally, overcoming known obstacles and ensuring that local policies and procedures reflect available research evidence and current best practice.

3.1 Planning for discharge of a child from hospital

3.1.1 Undertaking a multi-disciplinary assessment of the child's needs

A systematic assessment process is essential to ensure that the child's and family members' health is fully appreciated and the full range of needs addressed in partnership (see Bibliography B: ACT, 2003; DH, DfEE, HO, 2000a). Getting the assessment process right for families is one of the most important factors in delivering an effective service that will meet individual and family needs; it is particularly relevant in the context of inter-professional and inter-agency working. A Common Assessment Framework in England is being developed (www.everychildmatters.gov.uk) based on inter-professional and inter-agency work. The aim of this assessment is to improve the quality and consistency of assessments of children's needs that can be used by the whole children's workforce as a common 'front end to more specialist assessments'. A number of these more specialist assessment tools have been developed specifically for long-term ventilated children or children with complex care needs. Bibliography B includes examples of assessment frameworks that can be downloaded from www.longtermventilation.nhs.uk and contains web-based links to the Common Assessment Framework consultation process being undertaken by the Department for Education and Skills.

There are two main parts to the assessment process:

- 1 agreeing the needs of the child and their family members giving due weight to the child's and parents' views, and
- 2 planning how to support the child and family (which may involve a number of areas, some directly related to the child and some more global, including physical, emotional, social and psychological needs).

There is a tendency for frameworks and assessment tools to be based around a needs or problem-based approach, rather than being outcome-based, and this may result in desired outcomes not being achieved. For example, if the outcome is for a parent to be enabled to parent their child rather than be continually seen in a caring or nursing role, it might not be appropriate just to take the care away but to identify ways of helping the parent learn how to parent their child within this context.

The assessment process can be viewed as the first stage in meeting and learning about the family, to build a trusting and interactive working relationship with them. It is also an opportunity to explore existing relationships and dimensions within a family, such as the challenges they already face, in addition to having to care for their child who is long-term ventilated. Limbrick (2003) advocates listening to the family story as a key component of the assessment process. Time spent at this stage of the professional–family relationship can be viewed as an essential and integral part of the caring process.

A central aim of the assessment stage of establishing a relationship with a family is to ascertain what the family members see as important for professionals to work with them on, and help them with. Professionals with expertise also have a major role in providing advice concerning the multitude of issues for which parents have no prior knowledge or experience to draw upon. For example, many parents cannot imagine living at home without the level of nursing support and technical back-up provided by the intensive care unit. In particular, parents may request that a team of highly trained children's nurses be employed to care for their child at home, which may not be appropriate or deliverable. Likewise, having got used to 24-hour care while in hospital, parents may not be able to envisage the benefits of having time on their own at home without the presence of carers, when they can be together as a family and parent their child.

Conflict about the amount and type of care can and does frequently occur. Conflict of this nature is distressing for parents who may not be able to envisage caring for their child without the level of support they desire, distressing for professionals who have experience of what is realistic and deliverable, and distressing for children who remain in hospital while these issues are resolved. In such circumstances, inexperienced professionals should seek advice from professionals who have expertise in these matters (contact can be made either via the local regional children's hospital or www.longtermventilation.nhs.uk). Parents can find it helpful to talk with other parents who have successfully made the transition home with their child. Parents often have a better idea of their needs once they gain confidence and competence, and have experienced some time at home with their child. Nonetheless, getting the right balance concerning the amount and type of care is very challenging. The principle here should be to find a balance that is deliverable in practice. It is often helpful for parents to know that there are flexibilities built into the care package that can be used when they require periods of additional support.

It is important that the family is given written copies of any assessment and resulting action or support plan, to be shared with other professionals; it is helpful if the family can consent, within

agreed rules of confidentiality, for information gained during assessment to be shared, so that parents can avoid having to repeat themselves.

3.1.2 Assessing the needs of parents

Parents are also entitled to a carer assessment to identify how they might be best supported in their caring role. In addition, parents may well be experiencing increased costs at the very time when they have reduced opportunities for working. The key worker should signpost relevant benefits that the parents may be eligible to apply for, and either refer them to a social worker or support them through the application process.

In England, there is a national strategy to support carers, *Caring about Carers: National Strategy for Carers*, which was published in 1999 (DH, 1999a). The objective of the strategy is to bring together a range of initiatives, around the three key themes of information, support and care, designed to address carers' concerns and give carers improved support. Resources, links and information can be found on the government Caring about Carers website (www.carers.gov.uk). The Department of Health (England) has recently published draft policy guidance on the Carers and Disabled Children Act (2000) and Carers Equal Opportunities Act (2004) (DH, 2005).

Social Services Departments are the lead agencies for developing local plans for carers and the distribution of Carers Grants. Obtain your local strategy for carers: one example from Stoke-on-Trent (*Caring for Carers in Stoke-on-Trent: a Joint Carers Strategy*) is available to download from www.stoke.gov.uk/content/ss/carers-strategy/carers-strategy-document1.jsp.

3.1.3 Identifying an appropriate model of service provision

In most cases, the decision concerning which model is most appropriate to deliver a complex package of services and resources to meet the identified needs of the child will depend on:

- the complexity of the child's needs
- the level of local expertise of NHS staff concerning children with complex needs
- the provision and capacity of local public services
- local commissioning policy and practice
- local service-level agreements
- local coverage by voluntary and private sector organisations, and
- budgetary considerations.

Before making a decision, it is advisable to seek advice from centres with experience of commissioning complex packages of care. Contact should be made with the local regional children's hospital, or members of the UK working party on long-term ventilation in children (who include representatives from the private sector) for advice concerning their experiences and the relative costs and benefits of the various models of service organisation and delivery (see www.longtermventilation.nhs.uk).

3.1.4 Obtaining agreement to fund a package of care

One of the main obstacles to discharge has been identified as difficulty in getting agreement to fund a package of care to enable the child to live at home. The main reasons for these difficulties appear to stem from the lack of data concerning the costs associated with providing a package

of services, and the inability of various budget holders to agree on who should fund all or parts of the package.

There are a number of principles relating to agreeing funding that should be applied. Firstly, the family should not be involved in discussions about funding or costs. Family members will inevitably be aware of this to some extent but do not need to be involved in the detail; this is not the family's responsibility.

Secondly, very early in the discharge process, it is important to involve those responsible for funding within the locality that the child will be discharged to. However, it is unrealistic to get full agreement about levels of funding until the full multi-disciplinary and multi-agency assessment has been completed, and care-package proposal fully developed and understood. The most appropriate way forward dictates that funding is agreed in principle at an early stage, but detailed and specific funding is agreed once the assessments and proposal are completed.

Discharge planning and processes should continue in parallel to obtaining funding agreements and not be stopped until funding is agreed. It is often the case that funding needs and requirements become clearer during discharge planning. It is good practice to ensure that any confirmed funding arrangements are for the full range of identified needs that are known at the time of discharge.

It works well if there is a pre-arranged pathway for agreeing funding and a process that can be followed, incorporating the notion of 'early warning' and an agreed assessment and care-package summary for those responsible for funding to be sent in due course. It is important that the right amount and type of information is sent so that decisions can be taken promptly, without those responsible for funding having to ask for more information or clarification. In some areas proformas have been developed between service providers and commissioners that ensure this process is streamlined. We have included the proforma used by the Lifetime Service here as an example (Box 2).

Box 2 The Lifetime Service Proforma: multi-agency care package proposal for the child with complex health needs

This proforma and format for presenting the care package proposal has been agreed by service commissioners locally and ensures that commissioners receive the information they require to make appropriate and timely funding decisions. The fundamental principle underpinning the proforma is that of the information presented being the culmination of a multi-agency assessment of the child's and family's needs, taking account of their views. Each of the headings and subheadings indicate the format for presenting the required information which should be a summary of information gained from the assessment.

1. Diagnosis and medical history
2. Prognosis:
 - the expected progression of the child's condition
 - any anticipated changes in family circumstances or needs
3. Family situation
4. Current management and care needs
5. Medical and nursing support
6. Social care support
7. Education: pre-school/school
8. General development
9. Home visit:
 - housing
 - risk assessment
10. Service required:
 - staffing provision
 - staff roles and duties
 - annual staff costs
 - annual non-pay costs
 - initial equipment costs
 - ongoing health equipment costs
 - environmental costs (adaptations)
11. Alternative discharge arrangements possible (and costs if applicable)
12. Reports from other professionals of relevance
13. Summary:
 - the child's needs and care complexity
 - parental wishes
 - agreed level of provision required
 - annual costs anticipated – including start-up and ongoing costs

The proposal should be sent to the delegated commissioner with an accompanying letter indicating the required response time and providing any further information not contained within the document.

In agreeing funding it is important for the family, service providers and commissioners to understand the requirement for any funding agreed to be subject to review on a regular (usually annual) basis. This ensures that the care a child and family receive continues to meet their changing and evolving needs, with the potential for the level of funding required to go both down and up over time. It is important that an understanding is developed between the commissioners and service providers about the need for some flexibility in the approach to funding in order to take account of, for example, long-term sickness of a carer. The long-term absence of a carer would place an extra burden on the family and mean that bank or agency staff would be required to provide some support and cover while other carers are being trained and assessed, or the carer is rehabilitated back to work. Similarly parental ill-health, for example, may mean extra cover will be required for short periods of time or as an emergency to help the family cope and to ensure the continuity of safe care for the child. Conversely, there may be a time when the family is able to manage with less care provision, for example during the summer months while the child is free of respiratory infections, and the scope of the care package costs can be reduced for a period of time.

In terms of funding, budget holders can now exploit the flexibilities incorporated into the Health Act (1999), which provide opportunities to pool budgets across health and social services when working together to fund a package of care.

3.1.5 Calculating the cost of the care package

This can be a daunting task as the costs involved can be very high. Generally, commissioners of services and budget holders require the costs of care to be calculated for a 12-month period. The assessment of need will outline the elements of the care package that have been tailored to the child and their family. For each of the services identified in the care package, a unit cost per hour of service is attributed. This can be done reasonably quickly by referring to the annual compilation of unit costs for health and social care produced and updated by the Personal Social Services Research Unit. This comprehensive resource covers staff costs across primary and secondary care in both health and social services, and factors in hidden costs and overheads such as employer's national insurance costs, pension contributions, staff training and travel. It also includes cost estimates for aids and housing adaptations undertaken by social services departments. The annual compilation of unit costs can be downloaded from www.pssru.ac.uk. In many cases practitioners can enlist the help of finance departments in compiling accurate costs of a proposed care package if they are given the required information in sufficient detail. It is good practice for the key worker to establish close links with designated finance departments.

Not all the services and resources in the care package will be covered in the annual compilation of unit costs (such as electronic equipment, disposable equipment and supplies, pharmacy supplies and medications). The following resources may also be useful for attributing costs:

- British National Formulary
- NHS logistics purchasing catalogues
- private and voluntary sector charges, and
- market prices.

There may also be locally negotiated contracts with suppliers, manufacturers and companies to supply goods and services at a fixed price. If the care package is to be provided wholly or partly by the voluntary or private sector, detailed costings will need to be obtained as part of the partnership agreement.

In relation to equipment, it is usually assumed that the device will have a life of 5 years and would cost 10–15 per cent of the total cost per year to service and maintain. Exceptions to this rule include items such as wheelchairs, which on average last children up to 3 years before they outgrow them.

As an example, we have provided cost estimates (Table 1), which have been calculated by the Lifetime Service, for Rachel's care package in the exemplar from Section 2. We have also identified, and where possible estimated, some of the hidden costs, such as recruiting and training carers prior to Rachel's discharge home. See also Section 3.1.13 for more information and cost estimates concerning the purchase of equipment.

In addition, Noyes (2004) has recently completed an economic study that estimated the costs of caring for children in various hospital, domestic and residential settings. The total support costs for 24 children living at home over the previous 12 months are given in Table 2. A comparison of the total costs of support in different hospital and home-care settings is summarised in Table 3. Further details and in-depth costing data are referenced in Bibliography L and can be downloaded from the document store at www.longtermventilation.nhs.uk.

Table 1 An example of costings for Rachel's first year of care

Recruitment of care staff	Resources needed	Cost	
Advertising			
Shortlisting	1 day G grade	£133.83	
Interviewing	1 day G grade	£133.83	
Liaising with recruitment service			
Total recruitment costs		£267.66	
Initial training of care staff	Resources needed	Cost	
Core training*	5 days G grade or equivalent	£669.15	
Supervised practice	Working 1:1 with trained nurse ** in patient's home for duration of shift until assessed as competent – likely to take 2 months (for 2 months costs F & B working together)	£15,636.44	Includes night and Sunday hours working but excludes bank holiday working
Trust mandatory training sessions	Assume 42hrs per carer in first year (x3 carers)	£1,122.66	Calculated at basic day cost
Total initial training costs		£17,428.25	

Ongoing staffing costs	Resources needed	Annual cost	
Night-time care 7x9hr nights	63 hours per week B grade	£40,614.73	Includes 8 days @ bank holiday rate
Daytime care 5x5hr days	25 hours per week B grade	£11,847.17	Includes 8 days @ bank holiday rate
Ongoing training and team meetings	Assume 4 hours each per month (3 carers)	£1,283.04	Calculated at basic day cost
Total ongoing staffing costs		£53,744.94	
Equipment	Resources needed	Cost excl VAT	
Ventilator	Two required (£4,800)	£9,600.00	
Batteries for ventilator (to be replaced every two years)	Two required (500)	£1,000.00	
Humidifier	One required (£1,600)	£1,600.00	
Suction machines	Two required (£600)	£1,200.00	
Nebuliser	One required (£600)	£600.00	
Oxygen saturation monitor	One required (1,000)	£1,000.00	
Carbon dioxide monitor	One required (£1,800)	£1,800.00	
Sundry items***		£500.00	
Disposable equipment	Calculated as an average from other similar care packages	£8,517.57	Average cost for 2003/04–2004/05 for codes 3013–3237
Total equipment		£25,817.57	
Total cost of package		£97,258.43	

Notes to Table 1

* May need to use guest speakers such as company reps or other specialist nurse ie infection control nurse.

** Assume this will be F-grade training and development nurse, however pre-existing experienced care staff may be available to provide some of the supervision needed.

*** May include items such as torch, equipment bag, seating for night staff, etc.

Table 2 Total costs of support for 24 children living at home over the previous 12 months, 2002 prices (Noyes, 2004)

Annual support costs of 24 children and young people at home		
NHS	£2,076,343	82.9%
Social services	£21,088	0.8%
Education	£171,424	6.8%
Charity/voluntary sector	£41,022	1.6%
Independent	£188,242	7.5%
Parents	£6,333	0.3%
Total	£2,504,452	100.0%

Cost category N=24 at home	Sum	Range of costs (min)	Range of cost (max)	Mean	Standard Deviation	% total cost
Equipment *						
NHS	£154,233	£1,894	£20,186	£6,426	£3,723	
Charity/voluntary sector	£5,606	£0	£3,058	£234	£795	
Parents	£6,333					
Independent	£7,116					
Total	£173,288	£1,894	£20,186	£7,220	£4,689	6.9%
Hospital services						
In-patient stays ~	£429,918	£0	£154,700	£17,913	£35,724	
Outpatient appointments	£14,476	£0	£1,260	£603	£307	
A&E attendances	£600	£0	£225	£25	£53	
Total	£444,994			£18,541		17.8%
Ambulances	£11,019	£0	£5,000	£459	£1,030	0.4%
Community health services #						
NHS	£60,470	£72	£7,353	£2,520	£2,219	
Charity/voluntary sector						
Total	£60,470					2.4%
Primary care services +	£20,788	£0	£3,776	£866	£789	0.8%
Social services **	£1,351	£0	£998	£56	£200	0.1%
Pharmacy ***	£48,179	£0	£10,556	£2,007	£2,741	1.9%

Cost category N=24 at home	Sum	Range of costs (min)	Range of cost (max)	Mean	Standard Deviation	% total cost
Disposable equipment and supplies ****	£195,183	£1,000	£15,876	£8,133	£5,211	6.78%
Education ++	£171,424	£0	£18,050	£7,143	£6,465	6.8%
Nursing care / personal care/respite ~~						
NHS	£1,141,477	£0	£158,369	£47,562	£59,995	
Social services	£19,737	£0	£13,871	£822	£2,859	
Charity/voluntary sector	£35,416	£0	£15,347	£1,476	£3,472	
Independent	£181,126					
Total	£1,377,756	£0	£181,126	£57,407	£63,710	55.0%
Grand total	£2,504,452	£10,008	£331,619	£104,352	£84,082	100.0%

Notes to Table 2

* Equipment: all items of electronic and non-electric equipment (for example ventilators and standing frames). Annual costs are calculated assuming a 5-year life of the equipment – apart from wheelchairs where 3 years is used for children; 15 per cent service and maintenance costs are included.

~ In-patient stays: costs used: mean cost of intensive care and high-dependency bed per day outside London derived from NHS Finance Manual and 11 fieldwork sites; mean cost of children's ward derived from NHS Finance Manual. In-patient costs per day cover all NHS services delivered in hospital apart from ambulance transport.

Community health services: for example, chiropody, occupational therapy, physiotherapy, speech therapy, psychiatry, psychology and counselling.

+ Primary care services: General Practitioner, opticians, dentist.

** Social services: including social work input, social services nurseries, etc.

*** Pharmacy: including all items available on prescription, including drugs, enteral feeds, oxygen, lotions, etc.

**** Disposable equipment and supplies: for example, ventilator circuits, tracheostomy tubes, disposable hand towels, bedding, dressings and tapes.

++ Education: excludes the basic cost of a school place, includes all additional support services (for example classroom support) and transport to and from school.

~~ Nursing care, personal care and respite: including nurses, carers, home helps, and respite care delivered both inside and outside the home.

Table 3 Comparison of total costs of 12 months support in different hospitals and home-care settings, 2002 prices (Noyes, 2004)

Model	A	B	C	D	E	F	G	H	I	J	K	L
Package	12 months	12 months	12 months	12 months	12 months	12 months	12 months	12 months	12 months	12 months	12 months	12 months
	Paediatric intensive care unit @ £1700 per 24 hrs	High-dependency Long-term ventilation unit @ £800 per 24 hrs	Children's ward @ £398 per 24 hrs	24-hour home care E grade nurses £184,987	24-hour home care 50% E grade nurses £92,494	24-hour home care B grade HCA £106,306	24-hour home care LA home-care worker £101,708	12-hour night home care B grade HCA £57,583	12-hour day care B grade HCA £48,723	Parent unpaid carers	High-dependency nursing home for disabled young adults @ £1,136 per week	'Home for Life' Royal Hospital for Neuro-disability Ventilator Unit for young people and adults @ £3,000 per week for basic care in outer London
			Team leader Grade F nurse 0.2 WTE £8,385	Team leader Grade F HCA £53,153	Team leader Grade F nurse 0.2 WTE £8,385	Team leader Grade F nurse 0.2 WTE £8,385	Team leader Grade F nurse 0.2 WTE £8,385	Team leader Grade F nurse 0.2 WTE £8,385	Team leader Grade F nurse 0.2 WTE £8,385			
Nursing and personal care ~~			£193,372	£154,032	£114,691	£110,093	£65,967	£57,108	£0	£59,072	£156,000	
Equipment *			£7,220	£7,220	£7,220	£7,220	£7,220	£7,220	£7,220	£7,220	£7,220	£7,220
Hospital services **	£620,500	£292,000	£145,270	£18,541	£18,541	£18,541	£18,541	£18,541	£18,541	£18,541	£18,541	£18,541
Community health services #	£647	£647	£647	£2,519	£2,519	£2,519	£2,519	£2,519	£2,519	£2,519	£2,519	£2,519
Primary care services +			£866	£866	£866	£866	£866	£866	£866	£866	£866	£866
Pharmacy ***			£2,007	£2,007	£2,007	£2,007	£2,007	£2,007	£2,007	£2,007	£2,007	£2,007
Disposable equipment and supplies****			£8,132	£8,132	£8,132	£8,132	£8,132	£8,132	£8,132	£8,132	£8,132	included
Social services ##	£5,412	£5,412	£5,412	£56	£56	£56	£56	£56	£56	£56	£56	£56
Education ++	£3,829	£3,829	£3,829	£7,142	£7,142	£7,142	£7,142	£7,142	£7,142	£7,142	£7,142	£7,142
TOTAL	£630,388	£301,888	£155,158	£239,855	£200,515	£161,174	£156,576	£112,450	£103,591	£46,483	£105,555	£194,351

Notes to Table 3

* Equipment: mean costs of equipment derived from 24 ventilator-dependent children living at home (see Table 2). For children living in hospital, it was assumed that they used hospital equipment.

** Hospital services: mean costs of all in-patient, out-patient and A&E services derived from 24 ventilator-dependent children living at home (see Table 2). For children living in hospital, mean costs per day included all pharmacy, and disposable equipment and supplies.

Community health services: mean costs of services derived from 24 ventilator-dependent children living at home (see Table 2), and 7 children living in hospital.

+ Primary care services: mean costs of services derived from 24 ventilator-dependent children living at home (see Table 2).

Social services: mean costs of social services derived from 24 ventilator-dependent children living at home (see Table 2), and 7 children living in hospital.

*** Pharmacy: mean costs of pharmacy derived from 24 ventilator-dependent children living at home (see Table 2). For children in hospital, it was assumed that pharmacy costs were included in the cost of a bed per day.

**** Disposable equipment and supplies: mean costs derived from 24 ventilator-dependent children living at home (see Table 2). For children in hospital, it was assumed that pharmacy, disposable equipment and supplies were included in the cost of a bed per day.

++ Education: mean costs of additional education services derived from 24 ventilator-dependent children living at home (see Table 2), and 7 children living in hospital.

~~ Nursing care and personal care: for children living in hospital, nursing care costs were included in the cost of a bed per day. Home-care costs were derived from Netten and Curtis (2002). Shift allowances were paid as follows: for NHS staff, weeknights and Saturdays x1.3 and Sundays/bank holidays x1.6; for local authority staff, Saturdays x1.5, weeknights x1.3, Sundays/bank holidays x2. Weekly costs of residential care were provided by the National Hospital for Neuro-disability, Putney, where costs include London Weighting and London Supplement (Netten and Curtis, 2002).

3.1.6 Direct Payment scheme

Some parents may choose to exercise their right to organise their own finances. Under the Carers and Disabled Children Act (2000), social services departments are empowered to make cash payments to parents of disabled children, and young people aged 16 or 17 years, in lieu of direct service provision. Making use of the Direct Payments development fund may allow children to get more individualised support and so facilitate greater social inclusion. On the other hand, the prospect of managing an annual budget may be an added stress rather than liberating to parents. Nonetheless some parents feel more in control and satisfied if they are able to manage all or some discrete aspects of their care package (such as the purchase of short-break care) to suit their needs.

Noyes (2004) found that agencies did not always actively promote Direct Payment schemes. However, the Health and Social Care Act (2001) does make an offer of direct payments mandatory in England, Scotland and Wales. Health and social care professionals need to be fully conversant with Direct Payments so that parents and young people can make informed choices about the management of their packages of support services. A wealth of information for children and their families (including a video and a guide written for young people) is available concerning the Direct Payment scheme, which includes accompanying guidance for healthcare professionals on how to support parents in their choices (see Bibliography L).

3.1.7 Getting multi-disciplinary, multi-agency, cross-sector service providers working together as a team

There is a well-established body of literature that addresses the question of what makes a successful and cost-effective partnership in terms of delivering multi-agency services across different sectors of provision (see Bibliography E). According to a recent study by Townsley and

colleagues (2004), research is no longer coming up with any new evidence concerning the factors that lead to successful cost-effective partnerships between organisations engaged in delivering packages of support services. Townsley and colleagues (2004) summarised the common success factors for effective multi-agency working, as follows:

- explicit agreement about how the partnership will pool or share resources such as time, people and money
- explicit agreement to a clear, shared vision that defines the purpose of the partnership, and common objectives for achieving that vision
- a clearly defined structure or model to explain how the multi-agency process will operate, particularly in terms of the nature of the work with children and their families and the expected outcomes for them
- clarification of the roles, responsibilities and contributions of the people involved in the multi-agency process
- effective leadership and the existence of allies and champions at strategic and operational levels within all organisations involved
- the provision of opportunities for learning, support and supervision
- clear and agreed management and accountability
- good communication between all those involved
- partnership with children and families
- regular monitoring and evaluation, and
- clarity about timescales and future planning.

Noyes (2004) found that many of these success factors were not evident in her study concerning the management and delivery of resources and services to children and young people with the most complex needs. Around half of the families in the study were dissatisfied with the co-ordination of their care packages and children did not gain maximum benefit from the high-cost services and resources provided.

Professionals should consider using Townsley's common success factors as a framework in order to get multi-disciplinary, multi-agency, cross-sector partnerships working together with common aims and a shared focus on the child and their family. Consider providing all parties with a copy of these success factors when the model of service provision is decided, and work through how you can best achieve this in practice.

The multi-disciplinary, multi-agency, cross-sector team

The professionals involved will vary according to the needs of individual children and the model of service provision adopted. In the case of Rachel, she is likely to have contact with the following professionals:

- **doctors**
 - paediatrician or anaesthetist from respiratory unit
 - general paediatrician in local hospital
 - general practitioner
 - community paediatrician
 - paediatric neurologist
- **nurses**
 - neonatal and children's intensive care unit nurses
 - key worker/discharge co-ordinator

- local community nurse manager (team leader)
- local hospital children's nurses
- community children's nurses
- agency nurses
- health visitor
- school nurse
- **carers**
- **therapists**
 - physiotherapist
 - speech therapist
 - occupational therapist
 - dietitian
 - pre-school/school staff
- **other professionals**
 - social worker
 - psychologist (clinical and educational)
 - ambulance service manager
 - commissioners of services
 - hospital/community/social services/housing/education business managers
 - depending on the model of service provision, managers from private/voluntary sector partnerships.

3.1.8 Bringing about effective key working

There is substantial literature concerning the benefits of key working and the resultant improved outcomes for children (see Bibliography E). The key worker should be working within the context of the integrated multi-disciplinary and multi-agency team, even if this team is a 'virtual team'. A number of different terms are used for the role of the key worker including, care co-ordinator, discharge co-ordinator, team leader or link worker. The key worker role is adapted according to local needs and is often initially undertaken by a person charged with organising the discharge of the child from hospital. Thereafter, the key worker role may be handed over to a person with responsibility for ongoing care management in the community. In some circumstances, the key worker may manage both discharge and ongoing care management.

Whatever the local title or remit, ideally the key worker will be experienced in the care needs of children on long-term ventilation and be of *sufficient authority* to liaise at all levels from senior to junior, within and across agencies (health, social, education, voluntary and private). Alternatively they should seek advice and guidance from specialists in the field in order to ensure the development of an appropriate care package, discharge process or ongoing care management. For example, members of the UK working party on long-term ventilation have considerable expertise in discharge management and can be contacted via the website (www.longtermventilation.nhs.uk).

It is vital that the key worker is conversant with relevant research as well as national and local policy and practice across all sectors of care provision. A major aspect of the role includes obtaining and reading research findings, information concerning policy initiatives and service development across all sectors, and up-to-date information concerning welfare payments. A core skill required of the key worker is the ability to appraise research evidence and implement, where appropriate, research findings and new policy initiatives that are designed to bring about better outcomes for children and their families. See also Section 3.5 for a further discussion on

implementing cross-departmental policy initiatives and guidance. The key worker should also communicate new information to the parents, the young person (where appropriate), and the care team. It is also of benefit to all practitioners if the key worker disseminates examples of good practice at a national and local level.

The Care Co-ordination Network UK (2004) has produced standards for key working with disabled children and their families that should be referred to as an example of best practice concerning bringing about successful key working (download from www.ccnuk.org.uk or www.longtermventilation.nhs.uk).

Even in ideal circumstances, key working is demanding, and as a matter of course processes, actions and outcomes should be documented carefully. If barriers to effective working in the form of people or policies are encountered (and this occurs commonly in practice), the key worker should arrange a non-confrontational one-to-one meeting with the relevant person(s). If the barrier(s) cannot be removed, then consider going higher in the organisation to a manager with sufficient power to facilitate multi-disciplinary, multi-agency working that focuses on the child and their family.

3.1.9 Managing the discharge process

Before discharge the child may be located in a neonatal or children's intensive care unit, high-dependency unit, transitional care unit, long-term ventilation unit or children's ward at a regional or local hospital. Wherever they happen to be, and whoever is identified as the provider of services (NHS and/or social services/voluntary/private sector organisation), the principles and steps to discharge are the same.

The National Service Framework for Children (England) emphasises the importance of discharge planning (Standard for Hospital Services, DH, 2003b). Taking home a child who requires long-term ventilation is a truly daunting task for the child, family and in many cases service providers. The task may even appear unachievable if it is the first time professionals and parents have encountered a child who requires long-term ventilation. Careful planning and preparation at a number of levels is vital for this critical transition. Bibliography B contains references to documents and provides links to some useful tools and examples of best practice that can be adapted locally to ensure appropriate and effective multi-agency discharge planning. In each locality there will be specific challenges and these tools can help the professionals involved to focus on the key issues that will improve the child's experience.

A whole-systems approach to discharge is advocated in a number of policy documents (see Bibliography B; DH, 2004; ACT, 2004) and encompasses assessment processes, commissioning and delivery of services. The discharge of a child requiring long-term ventilation is a process that needs to be planned across agencies with the individuals who are engaging in that process understanding and contributing to decisions that will need to be made. This process works best if it is co-ordinated by a named person (key worker) who is responsible for co-ordinating all stages of the child's journey at this time.

If they are available, effective use may be made of transitional and intermediate care services in order to optimise hospital, usually children's intensive care, capacity. However, the steps to discharge will be the same whatever environment a child is being discharged from.

The key goals to discharge planning are outlined in Box 3. Central to the discharge process is the development of a partnership with the parents, or in some circumstances an alternative carer for a child. They need to understand and be able to participate actively in the process and be given information and advice so they can make informed decisions. Parents who have a child needing complex technological care have commented on how they feel shocked and devastated by the uncertainty of their child's illness and their future. In addition to technical and clinical information relating to their child's condition, it is important that they are given information and made aware of important issues that relate to the reality they will face on taking their child home (Rawlinson et al, 2005). There are both positive and challenging aspects for parents, and it may be helpful for them to be in contact with other parents who have shared a similar experience. In the case of Rachel who is featured in the exemplar, there is a support network called 'CCHS family support' (www.cchsupp@hotmail.com). Other support networks can be accessed via the Contact a Family Directory (www.Cafamily.org.uk).

Box 3 Key goals in discharge planning

- To understand the local community and the range of services available to meet health, housing and social care needs.
- Ensure individuals (children and young people) and carers (parents and extended family members) are actively engaged in planning and delivering the care.
- The role of parents and other carers is recognised and their own rights for assessment and support acknowledged and met.
- Ensure effective communication between primary, secondary, social care, education and voluntary sector to focus care on meeting the needs of the individual child and their family.
- Agree, operate and performance-manage a joint discharge policy facilitating effective multi-disciplinary working at all levels and between organisations.
- Provide appropriate training for those undertaking care and co-ordinating roles.
- Begin preparations for discharge as early as possible, setting realistic timescales and targets.
- Develop an integrated discharge planning team to provide specialist discharge planning for the patient and other members of the multi-disciplinary team. This specialist support may need to be provided by a centre or area with previous experience of working with children with complex needs at home.
- Facilitate trial periods outside the hospital setting before any definitive decisions on longer-term care-package options are made.
- Funding decisions relating to NHS continuing care, social services and education provision should be made promptly so that discharge plans and eventual discharge are not delayed.

(Adapted from DH, 2003d)

3.1.10 Discharge checklists

It is important to document the entire discharge process, and there are a number of discharge checklists that have been developed and implemented (see Bibliography B for additional examples, and www.longtermventilation.co.uk). The example shown in Box 4 has been developed by the Lifetime Service in Bath.

Box 4 Example of a checklist for discharge planning

Bath & North East Somerset PCT

Discharge planning for ventilator dependent children

These plans are intended for use as a guide only and will need to be modified in order to meet all of the individual child and family's requirements. The plans are written as a simple guide, but it should be remembered that each stage can take many weeks to achieve so should be started as soon as possible after a child is identified as needing LTV.

Name of child

Consultant

Co-ordinator (key worker)

Named nurse

Discussion stage	Aims, comments and who will action this point	Date achieved signed
<p>Multi-disciplinary meeting to involve:</p> <ul style="list-style-type: none"> • parents & child (if appropriate). • medical and nursing staff (hospital & community) • Primary Care Team (GP, HV, DN) • Health Authority/Social Services representatives • others as appropriate. <p>All involved need to meet and assess the needs of the child and family.</p> <p>Provide family with verbal and written advice.</p> <p>Identify a key worker to co-ordinate package and liaise with all involved.</p> <p>Notes.....</p> <p>.....</p> <p>.....</p>	<p>To decide whether long-term ventilation is suitable and manageable for the child and family.</p> <p>To agree the care package that will be required.</p>	

Planning stage	Aims, comments and who will action this point	Date achieved Signed
<p>Funding Proposal of care needs and costs to be forwarded to PCT for agreement to fund care.</p> <p>Equipment Establish child on equipment suitable for home use.</p> <p>Does house need adaptation?</p> <p>Training parents Ensure parental involvement in care. If not already started then start training parents in every aspect of child's care. This should be documented and follow a written plan.</p>	<p>To include:</p> <ul style="list-style-type: none"> • general care of the child • use of equipment • what to do when things go wrong • basic life support. 	

Arrangements	Aims, comments and who will action this point	Date achieved Signed
<p>Recruitment of home-care staff Develop job descriptions, etc.</p> <p>Training carers Develop protocols, relevant training package and assessment tools.</p> <p>Commence training of care staff in hospital so carers are supported by staff who know the child well. NB Training and orientation of carers needs to continue when the child is discharged.</p> <p>Notes.....</p> <p>.....</p> <p>.....</p>	<p>To include:</p> <ul style="list-style-type: none"> • general care of the child • use of equipment • what to do when things go wrong • basic life support • information about working in someone's home. 	

Arrangements	Aims, comments and who will action this point	Date achieved Signed
<p>Training carers (cont.)</p> <p>Risk assessments need documenting, eg:</p> <ul style="list-style-type: none"> • assessment of home • safety of child • use of equipment • availability of community support. <p>Prepare action plans for family to use if child becomes unwell – to include readmission procedure.</p>	<p>Parents may wish to be involved in helping to teach carers about their child.</p> <p>This needs to be shared with:</p> <ul style="list-style-type: none"> • GP • ambulance service • emergency dept. 	

Arrangements for home	Aims, comments and who will action this point	Date achieved Signed
<p>Equipment</p> <p>Prepared a written list of all disposable equipment and set up an ordering system.</p> <p>Arrange how electro-medical equipment will be serviced/repaired. Consider where you will get back-up equipment from if needed.</p> <p>Contact utility companies to place family on priority lists.</p> <p>Contact ambulance service and accident & emergency department to place family on priority lists.</p> <p>Notes.....</p> <p>.....</p> <p>.....</p>	<p>Look at local procedures for ordering in the community.</p>	

Arrangements for home	Aims, comments and who will action this point	Date achieved Signed
<p>Assessment of carers</p> <p>Ongoing support of care staff</p> <p>Organisation of the care rota</p> <p>Check follow-up care is in place from other services as necessary, eg respite, occupational therapy, education.</p> <p>Arrange trial home visits.</p>		

Discharge home	Aims, comments and who will action this point	Date achieved Signed
<p>Multi-disciplinary team meeting to review progress to date and confirm child, family and care team are ready for discharge.</p> <p>Prescriptions arranged</p> <ul style="list-style-type: none"> • oxygen • medicines <p>Transfer of care co-ordination responsibilities</p> <p>Transfer of medical responsibilities to primary care</p> <p>Discharge letters completed and signed: these should be faxed/ emailed to primary care, ie GP & HV.</p> <p>Date planned for review meeting Date planned for outpatients Discharge home</p> <p>Notes</p> <p>.....</p>		

3.1.1.1 Managing a discharge meeting

Parents have reported consistently that discharge meetings are managed inefficiently and fail to bring about the desired action to enable their child to be discharged home (Noyes, 1999a). Inaction and disorganisation leading to a lack of progress can be very frustrating to parents and professionals alike. It is important that effective procedures are developed and put in place to minimise delays and prevent families feeling an overwhelming sense of frustration that can potentially lead to a breakdown in effective communication and working partnerships.

Indicators of success for managing an effective discharge meeting can be grouped under three headings: organising the meeting, managing the meeting, actions following the meeting.

Organising the meeting

- The key worker should organise the meeting and receive administrative support from the NHS Trust/organisation. The number and timing of the meetings can be scheduled in the discharge checklists at strategic points during the discharge process.
- The most important people to liaise with are the parents and if appropriate the young person involved.
- Draw up a contact list (preferably including email addresses) of all professionals with a stake in the discharge and ongoing care management of the child. In deciding who should attend a meeting, it is important that the purpose of the meeting is clear so that those who are in a position to make an active contribution to the agenda for the meeting are invited. When decisions are required, those who have the ability to take the decisions need to be at the meeting, or devolve levels of responsibility to a person deputising for them.
- Develop a core team of representative people who have a major role in the discharge process. All other professionals can be updated of progress via the minutes of the meeting.
- Check with the parents for two or three dates when they are available. Circulate these dates to the key professionals on the mailing list. It may be impossible to gather all professionals together at the same time, so consider asking people to send a deputy as long as it is clear that they are able to make an active contribution. Some professionals find it easier to teleconference if the distances involved necessitate an entire day away from their workplace.
- Book a suitable venue and organise drinks to be available.
- Send written details of the meeting, including an agenda, a map, travel options and if appropriate parking permits to attendees, and ask them to confirm their attendance.
- Preparation of those attending the meeting is key. Where relevant it works well to circulate papers for discussion before the meeting, and to ensure everyone is clear about the purpose of the meeting and anticipated outcomes. This can be done through phone calls to relevant people.
- It is imperative that the key worker involves the family in preparing for a meeting, so that family members are both fully supported and prepared, and so that they do not have unrealistic expectations of anticipated outcomes or timescales.
- Do not cancel the meeting unless there are exceptional circumstances. If the meeting has to be cancelled, inform everyone in writing, or if there is not enough time for this, telephone in person.

Managing the meeting

- The role of the Chair of the meeting is vital. The Chair should have experience in managing family-orientated meetings and aim to keep the agenda to time. It is important at the beginning that introductions are made and roles clarified, as well as the purpose and structure of the meeting reiterated.
- Families like professionals to wear name badges.
- The Chair should be aware of the need to include the parents, and if appropriate the young person, in the discussion at every stage.
- It is helpful if the agenda is focused on the child and family in question, structured around a discharge checklist, and medical jargon is not used.
- A discharge meeting should not be the forum used to agree or dispute funding arrangements, and the family should not be involved in any such issues. The concern and focus of the meeting should be about establishing the needs of the child and their family, and agreeing how these needs can best be met, and by whom within the local area.
- Action points and the people identified as being responsible for undertaking the action should be recorded in the minutes. This will include both professionals and family members.
- It is vital that timescales and dates for reviews are included. Minutes should be circulated promptly following the meeting (including to parents and if appropriate the young person).
- It is good practice for the key worker and/or Chair of the meeting to spend some time after the meeting debriefing the family members and ensuring that they have understood what has been discussed and what the next steps will be.

Actions following the meeting

- It is the key worker's role to follow up on actions and ensure that they have been completed within the timescales identified by the responsible person or service.
- At subsequent meetings the agenda should start with a review of action points, updates and outcomes from the previous meeting.
- If the discharge process stalls it is important to identify the specific reason as soon as possible and consider having a one-to-one meeting with the relevant service manager involved.
- If the reason is beyond the control of professionals (such as the family waiting for its home to be adapted), look for innovative solutions and seek advice from professionals who have successfully managed challenging situations that act as a barrier to progress.

3.1.12 The parents' role

The parents' role in the care of a long-term ventilated child cannot be assumed. The level of involvement they are able and willing to provide, and the amount and type of support they require in order to do this, will need to be assessed at an early stage of the discharge process. A key dimension for parents is their role as informal carers, which involves them undertaking in many circumstances a significant extension of their parenting role. It is now recognised that this also impacts on the nature of their relationships with professionals and requires a change from traditional roles (Kirk, 2001).

Limbrick (2003) advocates a process of negotiation in order to establish a parent's role and introduces the notion of parents as co-workers. However, this can only be achieved if the

parents are fully informed about the implications of them undertaking this role, they are properly prepared and trained and support systems are in place to assist them in their role. This should include emotional support as well as training and mentoring in relation to specific skills.

A model of service should be developed that embraces the notion of child-focused care (NSF for Children (England) and Limbrick, 2003) where the parent's central role and expertise is recognised. It is important that practitioners and family members are working towards agreed goals and that responsibility and levels of involvement are both negotiated and agreed. A number of factors influence the nature of the parents' role in each individual case and this will need to be ascertained at the first assessment stage. Box 5 provides examples of this (and refer to the assessment of Rachel's family circumstances in the exemplar in Section 2).

Box 5 Examples of factors that may influence parents' roles

- Are they emotionally ready to take on the task required of them?
- Do they have the parenting capacity to undertake this role?
- Are there other factors (financial difficulties or relationship problems) that will inhibit their capability to be involved?
- Do they have time during the day? What are the other demands on their time? Are there siblings who will require attention?
- Is there space in the home for the necessary activity and equipment?
- Is there any extended family support available to the family?
- Would the parent prefer some time when they can be 'just a parent'?
- What are the family members' commitments to paid work?

(Adapted from Limbrick, 2003)

A parent's ability and wish to be involved with their child's care may vary during the course of the child's illness, and mirrors a number of factors including their own adjustment and coping with the situation, other aspects of family life and the trust they have in existing support services.

In order to work successfully with parents being involved, there are a number of areas where it is useful to have developed some shared understanding and ways of working. These include:

- Preparing for the role: this may involve meeting other parents, psychological support, promoting realistic expectations, a flexible approach and building in a process of regular reviews so that the parent's level of involvement and wishes can change at any time in response to needs.
- Agreeing relevant goals that are child-focused and outcome-based.
- Working with parents so there is shared understanding about the approach required for the individual child and family situation.
- Working with the parents to ensure the activities are enjoyable for the child and parent. This may involve finding ways to integrate the child's care and treatment into daily routines and play.

- Agreeing roles and responsibilities of parents and carers: for example, in relation to undertaking household tasks, the child's leisure activities, medical and nursing care, equipment and ordering tasks. This involves setting boundaries to ensure clarity and prevent misunderstandings, duplications or omissions.
- Do not presume that a parent will undertake all tasks, and do not burden them with too many 'tasks' as they still need to be a parent and the child needs to see and know them as one.

In addition to Contact a Family (www.cafamily.org.uk), there are a number of carers' organisations that aim to support parents, such as Carers UK (www.carersonline.org.uk) and the Care Co-ordination Network UK (www.ccnuk.org.uk). See also Section 3.1.2 above, on assessing the needs of parents.

3.1.13 Purchasing and maintaining equipment for long-term ventilated children

Long-term ventilated children require equipment, and in some cases adaptations of equipment, to enable them to be able to manage at home safely. Delays in completing assessments and arranging any necessary equipment can cause considerable problems and significantly delay training for parents and carers, and discharge home. Depending on the child's underlying medical condition, the type and range of equipment required will vary and may include 'community equipment' (for example hoists, beds and seating), equipment relating to the child's underlying medical condition or disability (for example wheelchairs), as well as the specialised equipment relating to the child's technological care needs (such as ventilators, monitors and suction machines). The focus in this guidance is on the latter. For guidance on the former, practitioners should refer to local and national guidance relating to integrated community equipment stores at www.icesdh.org.uk and involve occupational therapists and physiotherapists from social services and the NHS (hospital and/or in primary care).

Community equipment

Generally, the equipment or adaptations required have been identified as falling into four categories (DH, 2003d):

- simple and easily transportable equipment that requires only minimal instructions for use, for example a bath or toilet-seating aid
- equipment that requires the carer to have training in correct use, maintenance and repair – this will often need delivering to the family home and may require installation, eg a hoist
- adaptations to the home following assessment by a therapist, where a grant may be needed to fund the work (see Section 3.1.15 on housing adaptations), and
- wheelchairs, both manual and electric.

There is a need to consider both the needs of the individual child as well as the safety of care staff who will be working in the family home. A balance needs to be found between the provision of equipment for the safety of staff, such as a hoist for moving and handling, and what is possible or feasible within a family home, that also meets with the wishes of the family. In addition, technological equipment is required to support children with complex needs, such as those using long-term ventilation.

Technological equipment

When it has been agreed that a child requires long-term ventilation, it will be necessary to start purchasing and using technological equipment that is suitable for home use. This is a specialised area of equipment provision where there is benefit in accessing advice and guidance from experts in the field. The local regional children's hospital and members of the UK working party on long-term ventilation have considerable expertise in this area. They may be contacted via the website (www.longtermventilation.nhs.uk). The following pages provide some information that may be used as a guide to those responsible locally for the child at home.

All children who require long-term ventilation will have very different needs, so this document outlines only the basic equipment that may be needed. The equipment should be robust and easy for parents and carers to use. Most electro-medical equipment has not been designed for the wear and tear it may be put under by a community-based child. A full assessment will be required to highlight the child's specific needs. However, here we have included some points to consider when purchasing equipment.

Ventilators

- The type of ventilator and the settings required by a particular child will be a medical decision.
- Do you need a ventilator, or would a CPAP unit be more suitable?
- Is the child medically stable using the machine?
- Will the ventilator 'grow with the child' or are you already at its maximum settings?
- Is there scope to increase settings during periods of ill health?
- Are there sufficient and reliable alarms on the machine to indicate disconnections or a blocked tube?
- Is the machine user-friendly? Will parents and carers be able to use it easily?
- Are other clients locally using the same equipment? This may reduce the need for training carers or ward staff looking after a number of children.
- Are the circuits suitable? External PEEP valves can be heavy and some exhalation ports may be easily blocked.
- Cost and availability of circuits: how often do they need changing?
- What emergency power source will you use?
- Does the machine have an internal battery? How long will it last?
- Does the machine have a DC input socket? What type of battery does it use?
- If the machine has no DC input, can you power it using an inverter and battery?
- Lead acid batteries are heavy; lithium ion or nickel metal hydride are about half the weight.
- How heavy is the machine? How heavy is the battery? Is the combined weight still portable?
- Will it fit into pushchairs or wheelchairs?
- Can you easily attach oxygen?
- How much does the machine cost?
- Do you have to sign up to the manufacturer's service contract? How much is this?
- Who will offer technical advice and support?

Humidifiers

- More BiPAP machines are now incorporating humidity into them, which makes life easier.
- Are you going to use a heated water bath or can you use a heat moisture exchange filter?

- If using a heated water bath, make sure the temperature probe, heater wire and circuit are compatible.
- Temperature probes need replacing, so budget for this and leave a spare probe at the house.

Oxygen saturation monitors

- Do you need to monitor oxygen saturations continuously overnight?
- Do you need to download this information at any point?
- Does the child need spot-checks during the day? You may need a portable machine as well.
- Are the probes suitable?
- Has the most suitable machine been selected to minimise motion artefact?

Suction machine

- Does the child need suction?
- If the child has a tracheostomy you will need two machines.
- If the child is at school you may need to purchase a third to use as back-up at school.
- Does the machine run on battery?
- Is it quiet? Is it easy to clean?
- Is the receptacle disposable? If so, supplies can take a lot of storage space.

Nebuliser

- Does the child need a nebuliser?
- Administering saline nebulisers is sometimes useful to prevent build-up of thick, sticky secretions in children with tracheostomies.
- Nebulisers are available with mains or battery power. Consider where it is to be used, ie home or school.

End-tidal/transcutaneous carbon dioxide (CO₂) monitor

Not all centres use these; however they are useful for monitoring changes in ventilator settings without hospital admission and for review of ongoing treatment.

- The type and usage of CO₂ monitoring will depend on the practice of the lead physician in the child's care, and local practice, as well as the type of ventilation and monitoring requirements that the child has and what they will tolerate.
- Can they be used with humidified circuits (normally main stream sampling devices, side stream likely to occlude but still possible to use)?
- Ease of use? Portability? Cost of disposables?
- If you have a number of children, this device could be shared between them for occasional monitoring (as long as it is cleaned appropriately).

Oxygen

- If regular oxygen is required, consider concentrators, liquid oxygen and cylinders.
- Consult local supply sources and contracts.
- Where will it be stored?

Uninterrupted power supply

In some areas it is custom to install an uninterrupted power supply (a generator) as back-up in case of a power cut; local arrangements will need to be made as this is more important for some families than others. For example, in a very rural area where it may take time for a supply

of electricity to be restored, it would be advisable to consider how to ensure continued ventilator use in the event of a power failure being longer than the internal battery can accommodate. Systems available are generally not recommended for home use although custom and practice is that they are used in a number of cases. Alternatively, portable back-up batteries or power packs may be supplied.

Points to consider with all electro-medical equipment

- Who will service it?
- Are you able to get a loan machine during times of breakdown or servicing?
- How will equipment be replaced during a 24-hour period? This may be via an on-call hospital electro-medical technician, by an equipment company, or by contact with an on-call nurse or service manager.
- What is the cost and availability of disposable supplies?

Making the equipment portable

In addition to the above considerations, and depending on the age of the child, it is necessary to work with parents to find ways that they can realistically transport the equipment. For example, adapting a buggy to carry an oxygen cylinder and ventilator will vary locally, but may involve a medical engineering unit making adaptations to the family's buggy. Similarly, it can be helpful to have a trolley adapted with an adequate number of socket boards and drawers for storage of disposables to be beside the child's bed for use during the night. Parents find different ways of transporting the necessary disposable equipment, such as suction catheters, and emergency equipment, in a variety of backpacks and bags. Parents new to this may find it helpful to speak to other parents about how they have managed such issues. In some circumstances it is useful to have a second piece of equipment in another setting that the child attends regularly. For example, a second suction machine in school, as a back-up and to prevent two pieces of the same equipment having to be transferred each day from home. It is not practicable for all equipment to be duplicated in this way as it is likely to be needed by the child during their journey, and the most efficient use of resources needs to be considered.

The equipment required by Rachel

Table 4 provides an example of the main items of equipment and their associated costs that will be required for Rachel, featured in the exemplar in Section 2.

Table 4 Summary and costs of core equipment that may need to be purchased

Equipment	Approximate cost
CPAP unit (NB you are likely to need two)	£300 – £500 each
Bi-level ventilator (NB you are likely to need two)	£3,000 – £12,000 each
Humidifier + leads	£1,800
Saturation monitor	£1,000 – £2,000
Portable saturation monitor	£200 – £600
Suction machine (NB you are likely to need two)	£500 – £600 each
End-tidal CO ₂ monitor	£1,500 – £2,000
Transcutaneous monitor	£1,800 – £2,200
Nebuliser	£200 – £500
Home oxygen concentrator; cylinders or liquid	Contact pharmacy or local distributors
Uninterrupted or back-up power supply	Contact specialist supplier

Notes to Table 4

For electrical equipment add 10–15% of purchase costs as an annual service charge.

Add 24-hour emergency call-out charges if these are not covered within service costs.

3.1.14 Disposable equipment and supplies

Long-term ventilated children require ongoing disposable equipment and supplies. Developing a system for ordering, delivering, storing and disposal of these that works for the child and family will depend partly on local practice. The main principle should be, however, that families and carers have access to the right amount and type of equipment at the right time. Storage of equipment can be problematic if storage space is not planned for. With administrative support, carers can be involved in partnership with parents in maintaining stock levels and re-ordering. It can work well for a simple order form to be devised containing a list of all the consumables that a child requires and for this to be used as a basis for ordering with whoever is responsible for ordering equipment locally. There is likely to be clinical waste (for example suction catheters) and local practice for disposal of this in the community will need to be followed.

It is important that an ongoing budget for disposable items is identified and agreed as part of the costed care package so that issues regarding funding do not arise once the child is discharged home. Systems should be put in place to ensure this budget is used efficiently and effectively, for optimum use of resources.

In general, disposable 'stock' equipment provided through NHS systems cannot be delivered directly to a child's home although 'non-stock' items can be. This means that a local health centre or GP surgery may need to be arranged as the place of delivery and a system established for that equipment to be taken to the child's home. This may involve collection by the parents or a family member, or a member of staff, and will be dependent on transport and location issues.

Noyes (2004) provides data on actual costs of mechanical equipment, disposable equipment and supplies incurred by a group of 35 children over a 12-month period (see Tables 2 and 3 above; Bibliography L; and www.longtermventilation.nhs.uk).

3.1.15 Adaptations to housing

Obtaining and completing adaptations to the child's domestic housing have also been identified as a major barrier that holds up the discharge of the child from hospital. It is advisable to refer the family to a children's occupational therapist early on so that an assessment can be made of their domestic accommodation. Standard 8 of the NSF (England) reinforces that the provision of effective and efficient housing adaptations, equipment and assistive technology requires close inter-agency co-ordination. It requires local authorities and Primary Care Trusts to ensure that commissioning of services for disabled children and their families includes consideration of their housing, community equipment and wheelchair needs. Local authorities are also required to map the housing needs of children and their families strategically and plan multi-agency resources and responses accordingly.

If adaptation work is required, the family may be eligible for a Disabled Facilities Grant (see Bibliography G for web-based links); but funding for this varies across the UK and with the ownership of the property that affects eligibility criteria. The Strategy Unit's report, *Improving Life Chances of Disabled People* (Strategy Unit, 2005) recommends that the Office of the Deputy Prime Minister considers reform of the Disability Facilities Grant in the light of the forthcoming review. Northern Ireland and Wales have already decided to remove the means test for this grant. Currently, if adaptation work is required, delays in discharge, whilst awaiting funding and completion of the required work, are a common feature.

Ways to minimise delays and reduce the inevitable stresses for the family will need to be found locally. Within local areas the ownership and style of housing varies considerably, including owner-occupied, local-authority and housing-association accommodation as well as privately rented homes. Local systems for funding, planning and provision of home adaptations can be a particular issue affecting the variability of discharge where there is a need for housing adaptations, for example if a child has physical impairments as well as requiring long-term ventilation.

For minor adaptations or repairs to make discharge possible, an occupational therapist (community) should be involved at an early stage. A local home improvement agency or handyman service, if available, will be able to help (see Bibliography G for further details).

Ideally, children with needs similar to those of Rachel in the exemplar would have a bedroom of their own so that siblings are not disturbed by the carers and machinery needed while the child is asleep. The bedroom also needs to be large enough to have a comfortable chair in it for the carer to sit in during the night, ideally placed away from the direct bedside, but within listening distance so the child can be attended to promptly. In some circumstances it may be preferable and feasible for there to be a separate room for the carer to sit in adjacent to the child's room with provision made (such as having the connecting doors open) to ensure the carer can safely and effectively monitor the child. This can provide privacy for the child or young person and allow the carer to have more light on, to undertake other activities.

Experience also suggests that carers who spend a lot of time in domestic homes with children who have very complex needs for health and social care prefer having their own facilities such as a separate sitting room and kitchen area. Some parents are willing and financially able to consider this when they either purchase or extend their domestic homes. Parents have also indicated that their privacy and family life is easier to maintain if carers have access to separate facilities. At present, Disabled Facilities Grants are means-tested, and limited to providing an appropriate living space for the child and not the carers. The lack of additional facilities for carers should not hamper the child being discharged home.

Other requirements in domestic homes include a suitable number of electric sockets to plug all the equipment into in the areas that the child will be accessing. It is important for the house to be fully accessible for the child so that they can be fully integrated into family life; so, the more space that can be created, the easier it is. In addition, dry storage space is needed for the supplies and spare equipment. In reality, if families own their own home, then adaptations may have to be undertaken as a series of steps as the child's needs change over time, and when they are able to afford it. Meanwhile, a children's occupational therapist and charities such as the Disabled Living Foundation (www.dlf.org.uk) can be invaluable in providing advice on resources and the best use of limited space within the home.

Access to the house is another consideration, for parents and carers to be able to move children and equipment easily in and out, as well as dealing with all the routine tasks required for children. Ideally, the house would have an outdoor area or garden. All other principles and requirements relating to disabled children and housing need also to be applied to a long-term ventilated child.

A number of organisations have developed templates and guidance around housing assessment. Some examples of these are referenced in Bibliography G, and can be downloaded from www.longtermventilation.nhs.uk.

3.1.16 Defining the term 'carer'

The term 'carer' may be used in a number of different contexts and it is important to clarify what is meant by a 'carer' in relation to children requiring long-term ventilation. Within this context, 'carer' is used to refer to a variety of non-professionally qualified personnel from a variety of agencies who are both paid and specifically trained to meet the daily care needs of a long-term ventilated child while they are well and medically stable. A 'carer' may have any number of job titles depending on local variations. Examples include: healthcare assistants, home support workers, home carers, family link carers, healthcare support workers and Crossroads workers.

The principle difference between a 'carer' and a nurse in this context is that a nurse has received a professional training and qualification enabling them to be fully responsible for clinical decisions and to apply their knowledge and skills to the care of a wide number of children competently. A 'carer' does not have this professional training or qualification and is therefore unable to make clinical decisions independently. They are trained to care for specific children in a safe and competent way while the child is well, following set protocols and procedures for all aspects of the child's care. Within these protocols and procedures, carers are trained to know when they have reached the limits of their remit and will seek help from either a parent or a qualified

nurse, according to the individual child's protocol and care plan. Carers can be trained to carry out complex procedures and care with carefully developed protocols that facilitate a flexible approach as well as ensuring the child's and carer's well-being.

Experienced carers can work with more than one child very successfully as long as they have received appropriate training and reassessment so that their skills and competence with both children are assured. They will generally however require help and guidance from the parents and/or medical staff if the child becomes unwell or deteriorates unexpectedly.

3.1.17 The process of recruiting carers

The process for recruiting carers will follow local human resources policies and procedures. There are statutory requirements that need to be followed; for example, prospective carers will have to undergo a Police Check. Advice and copies of recruitment policies and procedures are available from your local human resources department. Some examples of job descriptions and person specifications are listed in Bibliography C, and available to download from www.longtermventilation.nhs.uk, for local adaptation. There is mixed practice regarding prior qualifications or experience required for these roles, and perhaps a pragmatic approach should be adopted that takes account of the limited workforce available for this type of work. However, some childcare experience may be beneficial. The recruitment process is a very important part of both the initial discharge of the child and the ongoing care at home as there can be issues of retention, particularly when carers are first recruited as they may not have understood the full remit of the role and only later realise that the work is not suitable for them. A number of local practices will exist and be developed to manage probationary periods for staff.

Strategies to aid recruitment and retention of carers, may include the following:

- Consider the level of involvement of parents, or parents' representatives in the recruitment process. If a team is developing to care for long-term ventilated children, where carers will be expected to train to care for more than one child, it can raise false expectations if a parent feels that at an interview 'their carer' has been appointed, but then goes on to work with other children.
- A two-stage selection process may be considered, whereby staff shortlist and interview carers initially and then an informal meeting with parents can give the prospective carer, staff and parent time to consider suitability for the job.
- Recruitment can be an ongoing process, and there needs to be an understanding with the parents regarding expectations of achieving a full and ongoing team over long periods of time. Inevitably, some excellent carers can use this sort of job opportunity as background experience before moving on to further roles within the caring field, for example.
- Training programmes, systems for staff supervision, mentoring and support all need to be in place to develop a team of motivated and effective carers. This is particularly challenging as the 'team' can be seen as virtual as not all members are based within one setting, and by working different shifts they can be quite isolated. This needs to be recognised from the outset and strategies developed to make support accessible. This may include some contact with staff out of hours.
- Carers will need to know that they will be fully supported during the period of practical training while they are gaining skills. During this time they need to work alongside someone (a trained nurse or experienced carer) who is already fully competent in all aspects of the child's care, and able to share their knowledge and transfer their skills. The newly recruited

carer will work alongside another person while they work through their practical training programme. It is important that the carer is not rushed or pushed to take on tasks alone until they feel able and confident to do so.

- Facilitating opportunities for ongoing development for carers, for example the availability of NVQ accreditation, can assist in maintaining interest and motivation as well as retention.
- Carers' team meetings and training sessions can bring team members together. Systems need to be in place to provide care for families at these times. Staff social events are also well received, for example an event to celebrate major religious festivals.
- Each carer should have a lead nurse who supports and supervises their practice, keeping in touch with them on an agreed regular basis using both telephone contact and meetings.
- The nature of the type of work carers are involved in is such that in some instances there can be an emotional impact on the carers. It is important to have resources available for individual counselling and support, either through psychology services or staff employment counselling services.

There are also a number of national policy initiatives around recruitment and retention, which are designed to guide managers in developing local recruitment and retention strategies. See Bibliographies C and D for references and additional resources.

3.1.18 Training and competencies of parents, carers and nurses

In order to support safely and effectively the care needs of children requiring long-term ventilation, a robust and comprehensive training programme needs to be developed and implemented. The programme should be based on competencies and supported by evidence-based protocols and guidelines. A key dimension in such a training programme in this context is the training and involvement in the child's care of non-clinicians (that is, parents and also the carers who work alongside them). In principle, a training programme will be designed by healthcare professionals to enable carers to care for a child who is medically stable, and to recognise the signs of when the child is becoming unwell and know how to seek appropriate help.

If the child becomes unwell they will need to be seen by appropriate clinical staff in a suitable setting, and cared for by appropriately qualified staff, not the trained but unqualified carers who care for them when they are well. In circumstances where the child receives joint care by a team of trained but unqualified carers and qualified children's nurses, then local arrangements need to be put in place as to whether the qualified nurses can look after the child's acute medical needs in a hospital setting. Such arrangements may include honorary contracts and opportunities for children's nurses who work as part of a care team in the community to update their experience of working in the acute hospital setting. Non-clinical carers should be trained by a healthcare professional to deliver care according to set protocols and guidelines and would not be expected to make independent clinical decisions about the child's care, but refer these to either a parent or a health professional.

The aim of a training programme should be to provide information and learning about both theoretical and practical aspects of the role and provide opportunities for supervised practice prior to an assessment of competence by a suitably qualified person, taking into account the parents' views and the views of the person being assessed. A programme of training for non-clinicians will generally be focused on the care of one particular child and although, with experience, some skills will be transferable to another situation, the individual carer would require specific training and assessment in order to participate in the care of a second or third child.

The elements of a training programme should include:

- acknowledgement of the child and parents as experts in the care (they too will need to be trained and assessed as competent)
- a competency-based approach
- written goals for individuals
- audit cycles
- evaluation criteria
- statements of accountability
- confidentiality
- the care of technological equipment
- social and developmental care, and
- emergency management.

One of the challenges frequently faced by the care team is the parents' confidence in the care team's ability to care for their child. It is important to cover this with the parents during their own training. When the parents are building up their own confidence and competence, introduce the concept that members of the care team will also be sharing their feelings during the initial stages of their training. This may help to allay fears later on.

Confidentiality should be a key element of the training programme. It is central to establishing and maintaining effective, trusting working relationships between the care team and families. It is a particularly challenging concept for nurses, carers and family members working together in the home setting in close proximity for long periods of time. There is a balance that needs to be found and maintained between being comfortable and communicating on a daily basis, and over-familiarity and the undermining of professional–friend boundaries. For example, it is important that carers and nurses do not share or divulge information about the family to other families they care for, or to people within their personal lives. It is equally important that parents respect the carers' responsibilities to maintain confidentiality and do not ask them questions or probe for information about other children and families they know or may also care for.

Examples of best-practice guidance, training programmes and competencies currently used in clinical practice are referenced in Bibliographies C and D, and some can be downloaded from the document store at www.longtermventilation.nhs.uk.

3.1.19 Assessing and managing risks

Healthcare is necessarily a high-risk activity, and risk management is about providing a suitable framework and opportunities from within which staff can make informed decisions, using sound judgement from a range of options. It must be remembered, however, that children using long-term ventilation do have rights under the Disability Discrimination Act (1995). This requires service providers to overcome physical barriers and to take reasonable steps to change practices, policies or procedures which make it impossible or unreasonably difficult for them to use a service. They must also be provided with auxiliary aids or services which make it easier for them to use a service. In all public sectors of provision, each Chief Executive has overall responsibility for risk management within their organisation, however, the requirement to manage risk is essentially a responsibility of all staff within the organisation. When working with private providers, clinical responsibility remains with the referring clinician, while the risk management concerning the services and resources remains the responsibility of the private

provider. In practice, many personnel working together in public/private partnerships to deliver a package of services find it beneficial to develop joint approaches to risk management and clinical governance.

Risk is defined as the possibility of incurring misfortune or loss. It can arise from the:

- clinical care provided
- clinical protocols and procedures in place
- equipment used
- people employed by or visiting the Trust
- communication/record systems in place
- management systems of the Trust, or
- environment.

Risk assessment

A risk assessment is a careful examination of what could cause harm to people, the environment, the organisation, to enable a review of whether enough precautions are in place or whether more should and can be done to prevent harm. All risk assessments should make reference to contingency planning and can be categorised into environmental, clinical and personal. Each NHS Trust or private sector company has a legal responsibility to identify and categorise risks and either eliminate or reduce them to the 'lowest level that is reasonably practicable'. Organisations will be obliged to follow local practice in registering risks and managing them.

Risk should be assessed against and included in the organisation's risk register and amended accordingly. A risk register is a way of logging risks that are difficult to control for, or that have not been resolved at an organisational level. Depending on the context, this process should lead to actions that bring about a change in practice or may enable individualisation of policies and procedures to suit the particular needs of a child and family. Good practice should mean close involvement and liaison with the organisation's risk manager and clinical governance leads.

These sorts of procedures can appear bureaucratic to families and it is important that they are helped to understand that organisations have obligations to comply with. If risk-management procedures are applied following the principles discussed within this guidance, they can be supportive and non-intrusive to family life.

The process of undertaking a risk assessment identifies the risks associated with providing care, as well as the systems that are in place to manage these risks (Box 6). The systems must be assessed as to whether they are sufficient or whether more should be done to reduce risk to an 'acceptable level'.

**Box 6 The five steps in the process of risk assessment
(Health and Safety Executive: *Five Steps to Risk Assessment*)**

- Step 1 Look for and identify the hazard/problem
- Step 2 Decide who or what might be affected and how
- Step 3 Evaluate the risks and decide whether the existing control measures/precautions in place are adequate or whether more should be done
- Use the Trust's risk-scoring matrix to assist with the evaluation of the severity and likelihood of the risk
- Treat the risk, ie decide what action to take. This could range from stopping the activity, to reducing the risk by introducing new control measures, to accepting the risk if it is minimal
- Step 4 Record the findings and communicate the risk and control measure to those who need to know – ie all people who could be affected
- Step 5 Review the assessment, looking at the effect of the risk and any actions taken

Within a hospital setting, control measures will be in place to manage many of the everyday risks associated with providing healthcare, such as: clinical wash-hand basins, alcohol gel, gloves and aprons and cleaning procedures to manage infection risks; manual handling equipment; and emergency crash call procedures. However, within the child's own environment most of the inherent control systems that are part of everyday working lives in the hospital will not be in place in the home environment and the risk assessment must identify how, and if, the risks can be controlled. If they cannot be controlled to an 'acceptable level' for the safety of both staff and child, it must be questioned whether care can be provided outside a healthcare setting. Within other settings such as play schemes or school, staff should also be trained in risk management and therefore actively contribute to this process and decision-making.

Although each assessment will be different, there will be core issues that need to be addressed in all assessments, such as:

- infection control
- communication methods – within the team and with the family
- emergency procedures – clinical and non-clinical ie resuscitation and how to manage an emergency evacuation in case of fire
- moving and handling
- the environment
- electrical supply and location of sockets for electro-medical equipment
- medical gas safety
- storage for medical supplies
- power failure – develop a procedure to manage in the event of a power failure
- ventilator failure – develop a procedure to manage in the event of a power failure, and
- lone working.

Risk assessment is an ongoing process and the assessment needs to be reviewed regularly to ensure that control measures are still appropriate. The need for regular review of the assessment when caring for children is especially relevant because of their changing ability and development. Control measures in place before a child could crawl or walk are likely to need updating before they begin to crawl or walk; this will include reviewing the positioning and location of equipment, sharps bins, and so on, so that they are out of reach of the child. If there are older siblings in the home, these control measures should already be in place to protect them.

The assessment should be reviewed annually and before any changes, which will include:

- prior to discharge
- at the time of discharge
- before any new treatment or procedures are started
- at times of staff changes
- when new equipment is introduced
- after a change of environment, eg house move, starting playschool or school, and
- after any adverse event or near miss.

It is perhaps not appropriate, or possible, to make a risk-free, childproof house and other family members' needs must be also accommodated. The child being cared for needs to be integrated into the family, and the challenge is to achieve a balance between reasonable risk and daily life. There are everyday risks that are managed by families, for example fire hazards, but within this context the additional risks that professionals need to work with families to address are those relating to carers and the child's technological requirements. In some situations, however, everyday risks become real risks that must be managed.

Where members of the family also assist with the provision of care, it is important to ensure that they have appropriate control measures in place. Consider providing training in moving and handling, and in basic life support to members of the family. Also review the control measures in place to see whether they in themselves could pose any risks. For example, the provision of latex powder-free gloves as an infection control measure will create a risk for a member of the family with a latex allergy. In these circumstances the Trust may consider providing alternative gloves for this person.

Use your organisation's risk-assessment template to document the assessment. The template used within the Bath and North East Somerset Primary Care Trust is provided as an example in Box 7.

Box 7 Example of a risk-assessment template, plus information on scoring risks

RISK ASSESSMENT TEMPLATE (complete all sections)

1. Risk assessment subject:

Assessment documented by:

Date documented:

2. Background:.....

.....

.....

.....

3. Description of risk:

.....

.....

.....

4. Control measures already in place to manage risk:

.....

.....

.....

5. Risk score with current control measures (see scoring matrix in Risk Management Policy)

Severity × Likelihood = Risk score

6. Details of additional control measures and action plan to manage risk:.....

.....

.....

.....

7. Anticipated resource implications (details and cost) £.....

.....

.....

.....

.....

Funding identified? Yes No Not applicable

Source of funding.....

8. Management responsibility and monitoring arrangements

Lead director

Start date for action plan

Identified lead for actions:

Monitoring lead
(eg committee or group, manager, SDIG, etc)

9. RISK REGISTER

Risk score: **1 – 9** Enter on Directorate Risk Register

Risk score: **10 – 25** Director to countersign assessment and forward to Risk
Manager for entry onto Risk Register

10. MONITORING

Date of review	Summary of current position	Current risk score
.....
.....
.....
.....

RISK SCORING MATRIX

Qualitative measures of severity – as a measure of magnitude

(see overleaf for additional descriptions to assist with the allocation of the severity score)





Level	Descriptor	Description
1	No harm or near miss	Near miss or no harm caused by adverse event
2	Minor	Minor temporary harm (first aid), Minor financial loss
3	Moderate	Moderate harm (medical treatment), Moderate reputation/financial loss
4	Major	Major harm (excessive injuries/RIDDOR), Major reputation/financial loss
5	Catastrophic	Any death, Excessive or intolerable financial/business/reputation loss

Qualitative measures of likelihood – as a measure of frequency

Level	Descriptor	Description
1	Unlikely	Event could occur but improbable/doubtful
2	Low	Event may occur at some time but rare/exceptional
3	Moderate	Event should occur at some time – FAIRLY likely
4	High	Event will occur in most circumstances – likely/probable
5	Certain	Event is expected to occur in most circumstances – no doubt

Qualitative risk assessment matrix (likelihood x severity = level of risk)

		1	2	3	4	5
LIKELIHOOD		Unlikely	Low	Moderate	High	Certain
SEVERITY	1 No harm or near miss	1	2	3	4	5
	2 Minor	2	4	6	8	10
	3 Moderate	3	6	9	12	15
	4 Major	4	8	12	16	20
	5 Catastrophic	5	10	15	20	25

Level of risk	 No or Low Risk 1–3	 Moderate Risk 4–6
	 Significant Risk 8–12	 High Risk 15–25

Additional descriptions to assist with the allocation of severity score

Severity Score	1	2	3	4	5
Descriptor	No harm/ near miss	Minor	Moderate	Major	Catastrophic
Objectives/ Projects	Insignificant cost increase/ schedule slippage. Barely noticeable reduction in scope or quality	< 5% over budget/ schedule slippage. Minor reduction in quality/ scope	5–10% over budget/ schedule slippage. Reduction in scope or quality	10–25% over budget/ schedule slippage. Doesn't meet secondary objectives	> 25% over budget/ schedule slippage. Doesn't meet primary objectives
Injury	No harm or near miss	Minor temporary harm/injury requiring first aid	Moderate harm/injury or illness, requiring medical treatment	Major harm/ excessive injuries (RIDDOR)	Any death
Patient Experience	Unsatisfactory patient experience not directly related to patient care	Unsatisfactory patient care experience – readily resolvable	Mismanagement of patient care	Serious mismanagement of patient care	Totally unsatisfactory patient outcome or experience
Complaints/ Claims	Locally resolved complaint	Justified complaint peripheral to clinical care	Below excess claim. Justified complaint involving lack of appropriate care	Claim above excess level. Multiple justified complaints	Multiple claims or single major claim
Service/ Business Interruption	Loss/ interruption > 1 hour	Loss/ interruption > 8 hours	Loss/ interruption > 1 day	Loss/ interruption > 1 week	Permanent loss of service or facility
Staffing and Competence	Short-term low staffing level temporarily reduces service quality (< 1 day)	Ongoing low staffing level reduces service quality	Late delivery of key objective/ service due to lack of staff. Minor error due to poor training. Ongoing unsafe staffing level	Uncertain delivery of key objective/ service due to lack of staff. Serious error due to poor training	Non-delivery of key objective/ service due to lack of key staff. Critical error due to insufficient training

Severity Score	1	2	3	4	5
Descriptor	No harm/ near miss	Minor	Moderate	Major	Catastrophic
Financial	Small loss	Loss > 0.1% of budget	Loss > 0.25% of budget	Loss > 0.5% of budget	Loss of > 1% of budget
Inspection/ Audit	Minor recommendations. Minor non-compliance with standard	Recommendations given. Non-compliance with standards	Reduced rating. Challenging recommendations. Non-compliance with core standards	Enforcement Action. Low rating. Critical report. Major non-compliance with core standards	Prosecution. Zero rating. Severely critical report
Adverse Publicity/ Reputation	Rumours	Local media – short-term. Minor effect on staff morale	Local media – long-term. Significant effect on staff morale	National media < 3 days	National media > 3 days. MP concern (question in House)

Sources of more information on different approaches to assessing and managing risk are listed in Bibliography D, and some further examples can be downloaded from the document store at www.longtermventilation.nhs.uk.

3.1.20 Attitude to risk of the child and family

The attitudes of children and their families to risk will mirror those of the general population. Individuals' attitudes to and acceptance of risk will lie somewhere on a spectrum from being completely risk-averse, to being accepting of risks in order to experience and enjoy a richer 'more fulfilling' life. Attitudes to risk and the consequences of taking risks will also vary over time for the growing child, and their parents, as they get more used to the child living at home.

It is important that as all children grow they experience 'healthy risk' in order to develop life skills and gain confidence in their own abilities. The issue with children who use assisted ventilation concerns the fact that some actions and activities would be considered a 'healthy risk' for the non-ventilated child but may have serious and sometimes fatal consequences for the ventilated child.

In general, parents tend to feel more comfortable about exposing their own children to 'healthy risk' than they would other people's children. Likewise, carers have an obligation to be more cautious with a child in their paid care than in making decisions that may be in the best interests of their own children.

Noyes (1999) and Ludvigsen and Morrison (2003) conducted research with parents and young people which found that the actions of professionals were frequently to eliminate risk whereas parents and children would accept a greater level of 'healthy risk' in order to benefit from increased social inclusion and more varied life experiences. At the same time, Noyes found that other parents had taken legal action and some had been awarded compensation when avoidable consequences had occurred.

Conflict can and does arise frequently when competing tensions exist between:

- professionals, who may seek to eliminate risks
- parents, who may be more risk-averse than professionals or alternatively more accepting of a greater level of risk than professionals, and
- children and young people who increasingly want less monitoring and adult surveillance as they grow up.

Examples frequently cited by parents of risk-avoidance they find excessive include: professionals' refusal to allow children to participate in school outings, sleepovers at other children's houses, visits to hotels and theme parks, and theme-park rides; refusal to close the toilet/bathroom/bedroom door to ensure the child has privacy; use of intercoms to listen in on children constantly; and the need for constant adult surveillance. The 'Dignity of Risk' (Lenehan and colleagues, 2004) offers a range of policies and practical advice on managing risk across a wide range of settings to help service providers take a proactive approach to risk management and ultimately to the inclusion of disabled children in everyday life. (see Bibliography D).

Managing risks is challenging, but experience indicates that the key factors to getting risk-management right for each individual child and their family include:

- listening to parents and children to find out their attitudes to risk and risk management, and how they want to live their life
- taking a flexible family-centred approach to each individual case
- deciding what is in the 'best interests' of the child and their family
- finding a consensus based on negotiation, when there are differences between the professional risk management action plan, the views of parents and the views of children
- making sure that professionals, parents and children are aware of the consequences of any course of action and checking that they are accepting of the associated risks
- seeking support and clarification from the risk management co-ordinator at your place of employment
- documenting decisions and the process by which decisions were taken concerning the management of risks and how checks and balances of risk have been made
- providing parents and children with copies of documentation outlining the process and agreed course of action, including where the parents decide not to embrace the usual service procedures
- ensuring that the key worker liaises with all carers, professionals and different agencies in order to implement a consistent risk-management approach
- ensuring that risk management is reviewed regularly as the needs of the child and their family change, and
- ensuring that carers and professionals undergo training in how to balance the wishes and rights of children and their families with professional issues concerning liability and conduct.

There may be situations when: a reasoned and reasonable approach to risk management cannot be agreed; the relationship between professionals and the family becomes irreconcilable; or professionals cannot work within their employer's policies or professional code of conduct. As a last resort, and following mediation, it may be appropriate to signal that the package of support may be withdrawn. Alternatively, some families have opted for the Direct Payment scheme whereby the parents or young person take responsibility for employing their own carers to support them in their chosen lifestyle. However, they must still put in place controls including risk assessment and training in order to effectively manage risk to carers they employ. (see Section 3.1.6 and Bibliography L for additional information and resources concerning Direct Payments).

3.1.21 Written procedures and protocols

Procedures and protocols should be written to incorporate the control measures identified in the risk assessments (see Bibliographies D and I for links to examples of documentation currently used in clinical practice). To minimise risks, all procedures and protocols should be written in accordance with the following three principles:

1. **To meet the needs of, and be appropriate for, the least-trained member of staff who will be working with the child.** It is important that these documents are not written to take account of the knowledge and experience of a trained nurse if they are also to be used by a carer trained especially to take care of the child. The procedures and protocols must be developed and written so that the least-trained member of staff will be able to follow them clearly and unambiguously.
2. **To include 'what if' scenarios and situations, which can be discussed and rehearsed in the training programme.** It is hoped that, if a thorough risk assessment is in place and reviewed regularly, unexpected emergency situations would not occur. However, it is always helpful and reassuring for staff to have time to discuss what might happen, and to practise how they would manage these situations in a safe, training environment. It is recognised however that it is not possible to pre-empt all potential events.
3. **To make individual adjustments for each household and each setting the child is accessing, as well as for each child and family's circumstances.** Generic procedures and protocols can only be used as a baseline but will never be transferable without adaptation and individualised adaptations.

It is important to note that although individualised protocols and procedures are written to reduce risk to staff they can, in some circumstances, also create a risk. The problem arises if staff members are working with two or more children that have similar but not identical procedures and protocols. It is foreseeable that in these circumstances, at some time, the member of staff will make an error. It is essential to recognise where this might occur and look at control measures that can be incorporated into the procedure or protocol to prevent the staff member making an error. Telling people that the protocols are similar but not the same will not prevent an error. Look at ways of making them obviously different, for example by ensuring that the care plan and documentation identify the child clearly, and highlight key features for a specific child in a summary sheet. Re-assessment of staff competence should be done for individual children and involve scenario training so that possibilities of errors can be rehearsed and risks minimised.

3.2 Delivering care in domestic settings

3.2.1 Health and safety in domestic settings

The NHS Trust, Social Services, Education setting, and/or the private/voluntary service provider has a legal duty to provide and maintain safe working conditions, equipment and systems of work for all of its employees and service users to the standards required by legislation and recognised good working practices. (See Bibliography D for user-friendly guides published by the Health and Safety Executive.) It is important to realise that these requirements also apply when providing services in a child's home. The home becomes the work environment for the staff and therefore it is important to include compliance with health and safety legislation in the risk assessment. Examples of health and safety legislation and guidance that should be included in the assessment include those on:

- moving and handling
- infection control
- lone working
- electricity at work
- medical gases
- Control of Substances Hazardous to Health (COSHH)
- disposal of clinical waste and sharps
- food handling and hygiene
- management of latex, and
- the work environment (eg day and night lighting and heating, seating).

The control measures in place within the hospital setting may not be appropriate for the home environment, either because of limited space or because the family may not want the home to resemble a clinical setting. It is important to document these facts within the risk assessment and to look at other options that might be available to control risks. For example, a hoist that would be used for the child in the healthcare setting may be too large for the home environment or unacceptable to the family because it would make their home resemble a healthcare setting. Another issue with manual handling equipment in the home is whether there is anywhere to store it safely when it is not in use. In these situations it is advisable to talk to the manufacturers of manual handling equipment. They may have a smaller hoist suitable for the child and the environment, a hoist that can be easily stored in small spaces when not in use, or a specific model for children that is colourful and therefore not so clinical-looking. Health and Safety legislation is in place to protect the child, staff and carers and can be used both to support safe practice and to allow innovation.

Some examples of risks that have been assessed, and clinical guidelines currently used in practice are listed in Bibliography I, and some can be downloaded from www.longtermventilation.nhs.uk.

Hand washing and hygiene in domestic settings

While recognising that the risks of cross-infection in the home setting are not the same as those in a hospital setting, the principles of infection control should be applied and adapted to meet the need for minimising risks of infection and cross-infection. Standard precautions for infection control are encompassed in a number of broad principles that can be applied to minimise risks

to the child and the risk to staff of acquiring occupational infection. (See Bibliography D for references to documents giving details of these.) These are risks that need to be managed effectively in order to achieve good standards of care. In this context these precautions should include:

- hand hygiene
- a clean environment
- waste management
- decontamination of equipment
- management of exposure to body fluids (Rayfield et al, 2003).

For specific advice and guidance, the local infection control lead should be consulted and involved in planning and reviewing these issues. The key principle should be to maintain a healthy and safe environment for the child within the context of the workplace being a home environment and not a hospital setting.

Hand hygiene

- Hand washing is the single most important measure necessary to prevent the spread of infections (Infection Control Nurses, 1999; Larson, 1998). It has been described as the cornerstone of all efforts to reduce the spread of infection (Rayfield et al, 2003). Nevertheless, satisfactory hand washing and drying is rarely achieved, and parents, carers and nurses will require specific training on infection control including hand hygiene, with regular reminders and updates being part of their ongoing training.
- The availability of a poster demonstrating the correct technique in the child's protocol folder or another prominent place can reinforce this training on a daily basis. Hands should be washed before and after an activity with a child that may contaminate the carer's hands. If a child is self-caring or touching/suctioning their tracheostomy, they will also need advice and guidance on hand hygiene.
- Drying is as important as the washing process. Local practice and advice should be sought about the method to be used for hand drying. If paper towels are not to be used, the availability of a clean hand-drying towel needs to be negotiated with the family, although generally terry towels for hand drying are not recommended (Infection Control Nurses, 1999).
- It is important that carers have access to a basin they can use within the home for hand washing (ideally with lever-operated taps), a liquid bacterial soap dispenser and a foot-operated waste bin. Alcohol hand gels or rubs can be used additionally as long as hands are cleaned with soap and water. If a carer has particular skin problems due to the type of hand detergent or gels, advice should be sought from the occupational health department (Rayfield et al, 2003).
- Carers should be encouraged to support hand hygiene by keeping their nails short and clean and by avoiding wearing hand jewellery with ridges or stones, and not wearing nail polish or false nails.

A clean environment

- Cleaning and disinfectant policies need to be adapted for home use. The underlying principle of working with families to establish effective and acceptable cleaning and hand washing procedures apply. Cleaning and additional disinfection should be carried out using an effective detergent to clean thoroughly and remove visible contamination such as dust, dirt and soils.

- Thorough cleaning of the environment contributes to the prevention of spread of resistant organisms. The aim should be for basic standards of cleanliness, particularly in relation to the child's environment and equipment, alongside using clean hands and clean cloths. Cleaning in this way removes micro-organisms, but does not destroy them, and disinfectant should follow cleaning if deemed necessary.
- Cleaning of the child's equipment and immediate environment should be planned into the daily routine in order to maintain a suitably clean environment. Ideally, suction units or other dirty equipment should not be cleaned in the hand washing basin. If there is no alternative, ensure that the hand washing basin is cleaned and disinfected thoroughly before being used again for hand washing.
- Drying equipment is as important as good cleaning, and the general principle should be to rinse thoroughly and leave things to dry on clean surfaces. For example, a nebuliser should be taken apart, washed in soapy water, rinsed in hot water and stood to dry on a clean surface or paper towel.

Waste management

- Local practice will dictate the application of waste management policies and whether yellow bags and collections of waste are required by the local authority.

Decontamination of equipment

- In addition to the principles of cleaning described above, local practice should be followed relating to decontaminating equipment, for example before it is transferred to another child to use, or before it is serviced.

Management of exposure to body fluids

- Carers may be exposed to fluids such as sputum, urine, faeces, vomit and blood. Universal precautions (the wearing of gloves and other protective barriers such as plastic aprons) are used for prevention of transmission of HIV, hepatitis B virus, and other blood-borne pathogens.
- Universal precautions should be implemented by carers in domestic settings to prevent contact with blood, other body fluids containing visible blood, semen and vaginal secretions.
- If sharp objects such as needles are used in the home, a policy should be in place to prevent injuries and potential infection by puncture wounds.

3.2.2 Key working once the child is home

Although the role may transfer to another person, key working does not end after discharge (see Bibliography E for relevant literature on key working). The key worker will have an ongoing role in organising responses to the child's changing needs over time, and to changing local circumstances. They should also organise regular meetings of the core team to discuss the child's ongoing needs and progress. They have a key responsibility for organising multi-agency reviews and reassessments, at least annually or more regularly if the child's changing needs indicate this. If the key worker role transfers at any time to a non-healthcare professional, alternative arrangements will need to be made in respect of overseeing the healthcare plan and training for the child's care in an education setting in order to meet DfES/DH guidance.

There is a need for ongoing multi-disciplinary follow-up by all professionals involved. One key part of this is the specialist follow-up and review relating to the ventilation, with opportunities

for the parents and young person to meet with and discuss their care with a range of appropriately qualified specialists. In some areas long-term ventilation clinics have been established where a family has an opportunity during an extended appointment to meet with members of the multi-disciplinary health team, so all aspects of their healthcare can be both reviewed and planned for.

To promote effective communication, it is important that agreement is reached with the family about sharing information, with the appropriate people, on progress and future plans. This can be done in the form of a shared information and documentation file that the family can hold and take to each appointment, and by letters to the parents summarising appointments and action plans being copied to a list of people agreed with the family.

3.2.3 The home as a workplace

There is a growing literature on parents' experiences of living alongside carers and the difficulties this can cause (see Bibliography H). Parents have indicated that one of the most difficult aspects for them has been the transition of their home into a place of work, and having to live alongside carers. Experience indicates that parents are often unprepared for this transition and the additional costs involved. For example, they may not have considered the need to heat their house overnight if a night carer is required, and many not have budgeted for the increased costs of heating and lighting, which are not usually reimbursed as part of the care package.

Some parents have voiced concerns about maintaining their religious and cultural traditions within the home. For example, conflicts have arisen concerning the dress and conduct of carers working in the homes of families who hold particular values, which are not shared by carers. Parents have also commonly expressed concerns about disciplining their child when the approach they adopt is not shared by carers. In particular, parents have said that some carers do not appreciate the noise they are making at night or the impact that their presence has on marital relationships and domestic life generally. Some parents have also described examples of unacceptable behaviour (such as taking family food). Moreover, these issues are made worse if there is a lack of co-ordination of the care package and a constant stream of professionals who either telephone or call at the house (frequently unannounced).

There is also growing experience from a professional perspective concerning the challenges of placing carers in domestic homes to work alongside families. For example, domestic homes are not designed with space for carers in mind, and working conditions can be cramped. Carers can also find it challenging to work in domestic settings, especially if they have been accustomed to working in hospitals. In addition, carers need to eat while at work, use the bathroom and take breaks. Issues concerning the carers' use of the family kitchen, bathroom and other facilities can be the cause of much tension. Carers can and frequently do become stressed by working with families with particular beliefs or lifestyles. Examples from practice include carers not being able to take certain foods into the house, carers who have found the roles of women within the household to be different from those in their own culture, or carers who have been monitored by the family on closed-circuit television. Carers can also feel that they are taken advantage of, and for a variety of reasons (such as lone working with parents of the opposite sex, being asked to prepare family meals or do the ironing) may at times feel uncomfortable working in domestic homes. Tensions can easily grow, leading to a high turnover of staff and dissatisfaction and stress among parents, professionals and carers.

Steps to engender good working practice in domestic homes include:

- Negotiating boundaries and identify acceptable working practices before discharge regarding the use of facilities within the family home. These can be documented in a shared document, sometimes called an agreement of care (examples of agreements of care are listed in Bibliography B, and can be downloaded from www.longtermventilation.nhs.uk).
- Helping parents and carers to identify potential areas of tension, such as who should provide milk and toilet rolls for use by carers.
- Drawing up agreed working practices into a set of house rules (an example used by Yorkhill NHS Trust is listed in Bibliography H, and can be downloaded from www.longtermventilation.nhs.uk).
- Providing training for both carers and parents in how to avoid and manage tension.
- Organising regular meetings between the key worker, carers and parents (separately and/or together) to flag up issues before they become problems.
- Implementing an early-warning system for both parents and carers when unacceptable behaviour occurs. (For example, one service issued a traffic-light system to parents and carers as an indication that an agreement has been broken.)
- Carefully documenting concerns and actions.
- Including sessions with a psychologist as part of the care package whereby parents and carers can work through issues and behaviours and find positive ways of coping and managing situations and difficulties, including ways to communicate effectively.

Despite putting into practice all of the above steps, unacceptable behaviour by carers should be dealt with in line with local employment policy and practice. Examples of unacceptable behaviour of carers might include not respecting the family's privacy, failing to follow protocols and procedures, or falling asleep. Continued unacceptable behaviour by parents or other family members would signal the withdrawal of the care team. Examples of unacceptable behaviour might include harassment (sexual or racial) or bullying of carers, excessive alcohol use, illegal drug use, any form of domestic violence or inappropriate punishment, withdrawal of parents from caring responsibilities or unplanned absence from the home.

There are several professionals who have a lot of expertise and experience in successfully managing the home as a place of work. Contact can be made via www.longtermventilation.nhs.uk.

3.2.4 The role of carers in relation to the family

It is important to clarify and emphasise the role of the carers during training and subsequent updates and assessments (see Bibliographies C and H for lists of resources). The focus of their role should always be on support and not to 'take over'. It can be very difficult for parents who, from the time their child has become unwell, may feel that they have lost control of their child's life. The objective of the home-care team should be to try and facilitate and enable parents to have as much control as they want or are able to take on at any particular time in the child's life. The approach requires flexibility and careful listening to the family's wishes. There may be occasions when the family needs the care team to 'take control' for short periods of time, if another family member becomes unwell for example, but the family will then need to be enabled to regain 'control' when it is ready for this.

Establishing relationships that can work well for individual families needs specific targeted work and negotiations (see also Section 3.2.3 on the home as a workplace). Clinical psychology input

with both carers and parents can work well both to prepare parents for the realities of 'home care' and to provide appropriate training for carers on the psychosocial care of families. Carers need to be trained to be 'professional friends', and at all times to respect the fact that their workplace is also a family home. This can be very difficult for both families and carers, and a source of potential tension, which can be minimised and resolved with good clear communication, building trust and mutual respect, and flexible and innovative approaches.

Achieving normal family life can be challenging, and it is important that carers understand that they do not necessarily have to be 'doing' things with a child all the time. The key principle is that of individualising the care delivered, and the corresponding training programme, to meet the child's care needs as well as the needs of the family and how they look after their children, which will be unique. This involves active listening at an early stage of working with families to try not to impose a service on them based on what professionals think the family ought to have, as opposed to what a family actually wants to happen. For example, a family may want to be left alone to play or eat together during the day, and may want the carer to leave the room for a period of time.

Who trains the carers?

It is important that parents' involvement in the training of carers is negotiated and that they are able to be involved. It is also important that parents have confidence in the nursing staff who are likely to be both training and assessing the carers. The nurses and key worker involved should spend some time on a regular basis with the child and be involved in delivering some of their care so that they maintain their skills and knowledge about the individual child's needs, and are therefore competent to deliver an ongoing training and assessment programme. (See Bibliography C, for examples of training programmes.)

3.2.5 Impact on family life

The impact of the child's discharge upon family life should be recognised (see Bibliographies H and M for supporting literature). Siblings may have to face additional responsibilities, restrictions on their freedom, loss of privacy and less access to quality time with their parents. The provision of care will also have both emotional and financial costs for the child's parents/guardians.

Common experiences described by parents/guardians caring for children at home are:

- loss of privacy and intimacy
- feeling anxious and depressed
- role confusion
- marital/relationship stress
- social isolation
- exhaustion and sleep deprivation, and
- guilt.

Opportunities should be provided for the family to express these feelings and concerns. It is the responsibility of the care team to provide emotional as well as practical support.

Children will also need ongoing support to allow them to live their lives as normally as possible. Dependence on a ventilator makes no difference to the human need for play and leisure. Children should be enabled to take part in such activities, and members of the care team can use their expertise to advise on how to facilitate the social inclusion of all family members.

3.2.6 Returning to hospital

The long-term ventilated child will inevitably need to return to hospital at some time following their initial discharge. If this ever became a lengthy hospital admission, plans should be put in place to ensure that the child maintains progress in their education while they are in hospital. However in general, the reasons for readmission can be divided into three distinct groups:

- 1 a routine admission for reviews (especially sleep studies, assessment or readjustment of ventilator settings)
- 2 an emergency admission relating to an acute change in respiratory function, and
- 3 an unplanned admission relating to a 'childhood illness', unrelated to but complicated by ventilation needs.

Each of these scenarios can be challenging but, with planning (both before and after discharge), can be managed appropriately and effectively, minimising both disruption to the child and their family and time in hospital. For children with such complex needs it is important that information about the child and their special needs is available to medical staff so that the child is treated appropriately and promptly. Plans for this can be put in place prior to initial discharge, for example with a summary of key points kept in the appropriate place within the hospital the child would access. It can be beneficial to have a care plan agreed with the family about how the child is going to be managed in the event of an acute illness, for example. For some children it may be that readmission is not in their best interests, or that if they are readmitted there are some agreed limitations about further treatment. Families and professionals need to agree, ideally in advance, what level of care will be accepted in the event of deterioration, and where the care may take place.

It is not possible or appropriate to provide within this guidance information that will cover all possible scenarios. On the following pages are brief examples of issues and some solutions that may be applied to a number of situations, the key principle being that the focus is on the child, not on traditional ways of delivering services.

Routine admissions

In many areas in the UK, when a child is readmitted to hospital for routine investigations (most commonly sleep studies, reassessment and readjustment of ventilatory requirements), they are admitted to a children's intensive care ward or high dependency unit as there is inadequate provision for them on more general wards. This creates a dilemma as the child is essentially a well child, but they have to be cared for in a hospital environment tailored for acutely sick children. It is important therefore to keep these types of admission to a minimum and to try and minimise the impact on the child of this experience.

In many instances, due to developing technology, sleep studies can be carried out in the family home using overnight monitoring equipment to record information that can later be downloaded for full analysis by appropriate medical or technical staff. Although undertaking the sleep study at home can be beneficial in terms of capturing a more accurate picture of the child's sleep within their usual environment, parents do like having the opportunity to discuss the results with professionals in person. This can be achieved through the provision of and access to a long-term ventilation clinic or dedicated appointment with an appropriate respiratory consultant.

There are inevitably times, however, when a child does have to be admitted to hospital. Local practice will need to be developed to decide how this is managed. For example, if a parent is unable to do so, will the child's own carers accompany the child and attend to them during the night alongside staff conducting the sleep study, to provide continuity for the child? This may be appropriate, and enabling a parent to sleep at night may mean that they are then able to be with the child during the day. In order to do this it may be that carers need honorary contracts with the hospital, and there will need to be clarity of understanding about roles and responsibilities. Carers will also require orientation and induction for this role, particularly so they can understand their role and know when and how to seek further help.

Emergency admissions

Long-term ventilated children can remain very well for long periods, but equally may experience changes in their ventilatory requirements, due for example to a respiratory infection, that means they become unstable and therefore unsafe to manage in a home environment. When this threshold is reached it is important that systems are in place to enable parents to seek appropriate and timely medical help from staff who have (or have access to) the expertise to care for a long-term ventilated child who is acutely unwell. In this scenario, the carer who may be working with the family is no longer trained appropriately to care for the child, who has now become 'medically unstable' and it will be the responsibility of the parents to access appropriate medical help via whatever means has been locally agreed. For example, they may have a 'direct access' arrangement with the hospital and be able to arrange immediate admission, or they may contact their GP. Or it may be appropriate to call an emergency ambulance. In this situation, pre-planning by informing the ambulance service about a child's specific needs in an emergency situation can be of great benefit. With the full information, the ambulance service will be able to send appropriate staff to assist the child. Consider providing the parents with a hand-held summary of their child's medical condition and treatment options, including a resuscitation guideline if discussed and agreed with the family.

Unless there is a particular reason, it is not generally appropriate for a carer to accompany the child to hospital as well as the parents, as this can lead to confusion by hospital staff who will perceive the carer as 'expert' in the child's care, not recognising their role as a carer of a 'well' child, not an acutely ill one.

Unplanned admissions

A long-term ventilated child is just as susceptible to childhood illness as other children, and on occasion may require hospital attendance or admission. As with other children, it will be the parents' responsibility to seek medical help and advice. If admission is required, local arrangements, as well as the nature of the illness, will determine where the child goes. For example, if the child has a febrile illness and convulsions, this can generally be managed in a children's ward at a district general hospital. However, staff in that unit may not have the skills to care for the child's ventilation needs. In this scenario it may be appropriate for the child's care team to accompany the child to hospital alongside the parents in order to provide the necessary care relating to the ventilation in partnership with the hospital staff. It is important that plans are made at the initial discharge so that there is an understanding of the scope and capability of the carer's role and extent of their responsibilities. It is beneficial to the child and their family to

avoid admission to an intensive care unit when they do not require that level of care, so developing plans to manage alternative scenarios can work well. It needs to be recognised however that not all situations can be planned for, and different solutions and plans will suit a variety of scenarios.

An important principle is that the parents should be allowed and enabled to be 'just parents' when their child has an acute illness, with provision for the child's care made appropriately. In some circumstances it may be that the local hospital staff can be trained to be able to care for the child appropriately, and staff from the hospital may rotate to work with the child in the community. However, there will always be issues relating to staff developing and maintaining competency and skills, especially when there is a turnover of staff, making it challenging to sustain adequate training.

3.2.7 Play, leisure, short breaks and family support

Long-term ventilated children have the same rights and choices to access play, leisure and recreational activities as other children, and their care packages should be organised to facilitate this (see Bibliography M). Activities and opportunities that are available to them will vary according to the local area but the same principles should apply. It can be challenging to find ways to allow the child freedom to integrate while being constantly monitored to ensure their health and well-being. The key principle should be that the child's carer follows the child to all settings, rather than there being different carers in each setting. This is important in order for the child to have some continuity and to limit the number of people they have to establish these sorts of relationships with. This supports the notion of competent carers who know a child well ensuring the child's safety in all settings. Agreements about funding differing aspects of this care and employment should be made using a multi-agency approach to the overall care package. For example, for Rachel, this might include her attending a holiday play-scheme accompanied by her carers, who remain employed by the health provider, but are funded by social services for this aspect of the care by pooling a budget for Rachel. The carers and play-scheme staff will need specific training and orientation both to work with Rachel and to understand how the play-scheme runs so they can work together to facilitate Rachel's full integration. KIDSactive (2004a,b) has produced best-practice guidance for including disabled children in play and leisure activities (for further policy and guidance in this area see Bibliography M).

Parents and long-term carers of the ventilated child are entitled to short-break care opportunities. Shared Care Network (Carlin and colleagues, 2005) has produced useful guidance on providing a range of quality services and examples of good practice (referenced in Bibliography M). There will be a range of provision locally, which may vary but might include local authority provision and, in some areas, children's hospice (although eligibility will be dependent on the child's diagnosis and practice within local hospices).

Whatever option a family chooses, the principles and practices presented in this guidance should be applied to the setting the child will be using. For some families it works best to have 'in-house' short-break care, where a carer who is fully competent to be left alone with the child for a defined period looks after the child while the parents go out for a break. If they are going away for a weekend, for example, it is important for the child to have continuity from someone they know well and who can take over parental responsibility. This may be a grandparent or close family friend. Parents will also need to provide a 'babysitter' for any well siblings in the family so the carer does not have to take responsibility for them at the same time as attending to the needs of the ventilated child.

Arranging short-break care and leisure activities takes time and careful planning. This needs to be done in partnership with the parents and child, to ensure that a full range of provision is explored, and the right option for each individual situation is found. It can be very difficult for parents to build up trust in an alternative person or service caring for their child, and they may feel guilty about asking for a break. They need to be helped to feel supported in their decisions, and fully listened to. It may be that the required provision is not available in a local area for a long-term ventilated child, and provision will have to be adapted innovatively to accommodate the needs identified. The same principle should be applied: the carer who knows the child well should be able to follow the child and provide the 'caring' in whichever setting is chosen.

These aspects of the child's care package should be reviewed and altered as necessary through the course of a child's life, to meet their evolving needs and the needs of the family members, and remain as an integral part of the care-package agreements.

3.2.8 Starting or returning to school

In this context, 'school' is used to include any educational pre-school or school setting. The same core principles should be applied to early years and education settings.

Children's rights and equality of access

The long-term ventilated child has the same rights to education as all children. Practitioners will need to familiarise themselves with the Department for Education and Skills Special Needs Action Programme (2003), and Government Strategy for Special Educational Needs (2004). The Disability Rights Commission has produced a Code of Practice for Schools on their responsibilities under Part 4 of the Disability Discrimination Act which came into force in September 2002. This makes the discrimination of disabled pupils unlawful and requires schools to change policies and practices that place a disabled pupil at a substantial disadvantage. The Act makes it unlawful for schools to treat a disabled child "less favourably" than a non-disabled child for a reason relating to their impairment. The Code of Practice can be accessed at www.drc-gb.org/thelaw/practice.asp. The Disability Discrimination Act (2005), which will become law in December 2006, will place a new duty on schools, as public bodies, to promote equality of opportunity and to eliminate unlawful discrimination. Under this specific duty, schools will be required to produce a disability equality scheme to show how they are planning to meet the need of disabled pupils.

Multi-agency working

The Special Educational Needs (SEN) Code of Practice (2001) provides guidance to local authorities, early education settings and schools on carrying out their statutory duties for identifying, assessing and making provision for children with SEN. The Code places a strong emphasis on education, health and social services working together to assess children's needs and develop packages of support to enable children with SEN, many of whom will also be disabled, to access education. The Early Support Programme, established in 2002, promotes multi-agency working around disabled children from birth to 3 years of age and their families. The programme supports activity in 49 local authorities and guidance and toolkits have been published for professionals and families which are available to download from www.earlysupport.org.uk and www.longtermventilation.nhs.uk. A good practice guide is available on supporting pupils with medical needs (see Appendix F for full references).

Risk management

The Disability Discrimination Act (1995) requires schools and other education settings to make reasonable adjustments to their policies and practice to prevent discrimination against disabled children and this often involves making an assessment of risks. The Health and Safety at Work Act (1974) requires employers to make an assessment of the risks of activities, introduce measures to control these risks and tell their employees about these measures. In some cases, children with medical needs may be more at risk than other children. Staff may need to take additional steps to safeguard their health and safety. The employer is responsible under the Act for making sure that all relevant staff know about and are, if necessary, trained to provide the additional support these children require.

Listening and involvement

Local authorities have a statutory duty to establish Parent Partnership Services to provide advice and information to parents on the statutory framework for special educational needs, their rights and the provision available locally. They must also make arrangements for resolving disputes between parents, schools and local authorities relating to special educational needs matters. The SEN Code of Practice emphasises the importance of schools and local authorities involving children in decisions that affect them including assessments, the development of Individual Education Plans and in annual reviews of their statements of SEN.

Planning appropriate support in education settings

The exact amount and type of special educational needs provision will be dependent on the nature of the child's underlying condition and their age and stage of development. There are, however, some particular dilemmas and key principles for this group of children that need to be considered. These are outlined in the rest of this subsection.

A representative of the local education authority should be part of the core team involved in planning and caring for the child or young person in the community, as soon as the child is of pre-school age. They will need to be involved at an early stage in planning for nursery/school attendance, agreeing levels of care, appropriate support, and special funding that may be required. An agreement should be reached about how funding should be split between the various agencies.

A school health plan will need to be developed in partnership with the parents, child and school nurse (refer to SEN codes of practice: DfES, 2001) in order to detail all care required and ensure that the relevant permissions and delegation of responsibilities are clear. The key worker should liaise with the school nurse who is unlikely to have had experience of a child with long-term ventilation needs. The school nurse will be able to provide expertise about the school and advice on ways of working that will be successful. They may also be involved in working with the teaching staff and the key worker in giving information to the rest of the school and the child's peers about the special needs of the long-term ventilated child.

The long-term ventilated child may or may not be otherwise disabled by a physical impairment, in addition to their medical and technological needs. The child may require help physically to access education, and assistance with their learning, as well as attention to their medical needs. This means there is the potential for a child requiring more than one member of staff to be

specifically available to them in an educational setting – for example, a child with a severe neuromuscular condition who requires two people to lift and move him. Local practice will need to determine how this care is provided but it may work well to have health funding one carer and education the other, but both carers must be trained in all aspects of the child's care and learning needs and be fully integrated within the school team.

The child may or may not have learning support needs, either as a result of their underlying condition or due to prolonged periods of hospitalisation. If the child has learning support needs they will require some additional help in school in addition to their needs for medical care. Depending on the level of learning support need, the child may undergo a statutory assessment which may lead to a Statement of Special Educational Needs. See the Early Support Programme guidance and toolkits on these matters (www.earlysupport.org.uk). Alternatively appropriate levels of support will be negotiated and agreed by education and health. Depending on the level of this need, local practice will determine funding arrangements. In addition, training for staff employed by a school to care for the child will need to be arranged and an ongoing training programme instigated for the skills of staff to be updated and reassessed. This training will be delivered by a healthcare professional.

If the child requires ventilation for parts of the school day, it may be that it works best for the health-carers who already know the child well, and can be specifically supported to deliver this higher level of care, to accompany the child to school and be given additional training relating to supporting the child's education from the school. Funding arrangements for this would need to be locally agreed but should not be allowed to prevent this sort of arrangement being put in place to provide continuity and a safe environment for the child to access education.

A child's inclusion within a school setting is essential in ensuring that they have as ordinary a life as possible. A balance will need to be found for the child, between the provision of appropriate care and attention from the carers or support assistants, and their need for privacy and space alone with their peers. Careful planning and contingency arrangements will be needed using creative and innovative thinking to achieve this key objective. For example, one young boy and his carer had a walkie-talkie each and he could contact the carer when he required assistance or suctioning while he went into the playground with his friends.

In some situations it may be appropriate for a range of people within the school setting to be trained in the child's care. This can achieve an objective of ensuring that there is always a member of staff available to care for the child rather than relying on one person and the child not being able to attend school if that person is off sick, for example. However, there is a need to ensure that all those who are actually or potentially caring for the child maintain their skills and competencies. This may be difficult to achieve if the skills are not being practised on a regular basis. It may be that the provision of a small care team of people within school who become 'experts' in the child's care can be developed, ensuring continuity and competence as well as avoiding reliance on one person alone.

As with all children with special needs, it is important that there are regular, ideally combined, health, social care and educational reviews. These can provide a forum for planning ahead specifically for the child's changing needs in respect of schooling, school trips or equipment needs, for example, in addition to the statutory educational review requirements. It may be that a smaller sub-group needs to meet to plan a specific event such as a school trip to ensure attention to detail and to ensure the child's needs for inclusion and safety are met.

It is important to recognise that starting nursery/school is a significant milestone for any child and their parents, and achieving this with minimal stress or deviation from normal practice will be very important for the child and their parents. Working proactively with families to begin planning for this transition early is important and can help prevent or minimise some of the actual and potential problems. It can also be important to normalise some of the concerns a parent may have about their child starting school in an educational setting. All parents worry, for example, about whether their child will eat at lunchtime, or develop friendships when they first start school.

The Council for Disabled Children is currently undertaking a project entitled *Health Needs in Education* that aims to develop materials for use in schools and early years settings which highlight best practice in supporting children with complex health needs. This includes children who require co-ordinated assistance in order to maintain optimum health during the school day, which may involve assistance with enteral feeding, catheterisation, assisted ventilation or those requiring emergency treatment. Best-practice guidance will be published in due course. Contact the Council for Disabled Children for further information (www.ncb.org.uk/cdc).

3.3 The young person's changing social needs and sexuality

Young people using long-term ventilation will vary greatly in the degree to which they have the freedom to organise their own lives and relationships. However, their right to live as ordinary a life as possible, enshrined with the Children Act 1989, must be balanced against risk factors. Like any other young person, they will want to develop their independence and the opportunity to experience peer friendships and relationships in private, and separate from their adult carers. For many young people using long-term ventilation, opportunities to meet with others and to relate in private may be limited, but they must be involved in risk assessment processes and enabled to make informed decisions about risk factors which affect the quality of their lives.

Young people should receive support with their changing needs as they get older, on topics including:

- making friends
- their sexuality
- accessing adolescent services
- accessing age-appropriate leisure facilities
- accessing further education or employment, and
- independent living.

There is a range of publications and best-practice guidance on managing the changing needs of young people. See Bibliography K, for sources of information.

3.4 Transition to adult services

Young people need support to participate actively in decisions relating to their ongoing care and their transfer to adult services. In particular, transition to adult services can be traumatic for young people who have established strong relationships with children's services over a long time. The key worker should co-ordinate the process and ensure that transitions to adult services are phased. They should include visits to adult service facilities and the gradual introduction of young people and their families to new professionals and agencies. Where appropriate, transitional care arrangements should be in place from 16+ for adult continuing care arrangements.

The NSF standard on Disabled Children and Children with Complex Health Needs (DfES, DH, 2004c), requires local authorities, Primary Care Trusts and NHS Trusts to ensure that transition planning has as its main focus the fulfilment of the hopes, dreams and potential of the young person, and in particular the maximisation of education, training and employment opportunities as well as the opportunity to enjoy social relationships and to live independently.

Transition to adulthood is one of the key chapters of the Strategy Unit's *Improving Life Chances of Disabled People* (2005) report, which outlines three key ingredients needed for effective support of disabled young people, to ensure that they enter adulthood able to participate and be included. These are:

- planning for transition focused on individual need
- continuous service provision, and
- access to a more transparent and appropriate menu of opportunities and choices.

The report anticipates that, over time, the introduction of individualised budgets will allow seamless transition from childhood to adult services. In the interim, it recommends that children's and adult services should overlap to improve continuity. This should be achieved through person-centred planning approaches and a Connexions service that is committed and equipped to support young disabled people.

As well as the NSF and Strategy Unit's report, there have been a number of other policy initiatives and pieces of legislation which address the issues of transition, including the Valuing People Strategy (with pilots in five local authorities developing links between person-centred planning and transition), Removing Barriers to Achievement – the SEN Strategy (DfES, 2004) and the extension of Direct Payments to 16- and 17-year-olds through the Carers and Disabled Children Act (2000). For key publications and best-practice guidance on managing transition, see Bibliography K, which lists sources of information.

3.5 Implementing cross-department national policies to improve outcomes for children with complex needs

There is a lot of research evidence to suggest that the care and services provided to children on long-term ventilation do not bring about the stated improved outcomes, and children and their families do not always experience positive benefits. Recent studies have found that many parents experience services as an additional stress as opposed to an added benefit. When parents complain about low-quality or inappropriate services that do not bring about the desired outcome, the response has frequently been to provide additional services which in turn add to

an already complex care package. Parents have reported that 'less can be more' and that they would prefer to receive fewer, but better-quality and well co-ordinated services that are shown to bring about the desired outcome for the child and their family. (For more information on these matters see Sudbery and Noyes, 1999; and Noyes, 2004).

As children on long-term ventilation have such complex needs for health, social care and education, they are often covered by multiple cross-departmental policy initiatives that are designed to improve outcomes of care and reduce health and social inequalities. In practice, this has turned out to be one of the most challenging aspects concerning organising and delivering care, as there are so many policies and initiatives to apply locally, and many have overlapping objectives. For example, in the case of Rachel who featured in the exemplar in Section 2, cross-departmental policy initiatives aimed at maximising her inclusion in society were far too numerous to reference in the exemplar, and are listed in Box 8.

Not surprisingly, health, social care and education professionals have found it difficult to stay abreast of these cross-cutting policy initiatives and in practice this has led to confusion and duplication, and the focus of care has strayed from providing a seamless and individualised package of services around the child. To counter this, it is essential that the key worker (or groups of key workers across a locality) takes a leading role in keeping abreast of these issues. It makes sense for the key workers across a locality to join forces and share information, facilitate multi-professional and inter-agency training, ensure that all professionals are up to date, able to take a strategic view, and can develop ways of working together locally. This should ensure that, where policies, initiatives and services overlap, or have overlapping aims, the child and their family receive appropriate, high-quality, well-coordinated services that bring about positive benefits and improved outcomes.

Box 8 Government cross-department policies and initiatives to promote Rachel's social inclusion (adapted from Audit Commission, 2003a, *Services for Disabled Children*; Noyes, 2004)

- The *Quality Protects Programme* aims to ensure that the needs of 'looked after' and disabled children are adequately assessed and met, enabling them to live with their families or other appropriate settings in the community (DH, 1998b).
- The Green Paper, *Every Child Matters* aims to ensure that every child reaches their potential through targeted services and child protection policies (DH, 2003c).
- The *Disability Discrimination Act* (1995) includes the duty to adopt a strategic approach, in partnership with local users, towards more accessible play and leisure services for disabled children.
- Part III of the Act puts duties on providers of goods and services, including, from 2004, to remove barriers creating difficulties in accessing the physical environment of a setting.
- The Office of the Deputy Prime Minister is issuing practical guidance on accessible play, and best-practice guidance on housing and adaptations (OPDM, 2004).
- The Department for Culture, Media and Sport has launched *A Framework for Action on Disability*, including a commitment to enhance access to cultural and sporting opportunities for disabled children (DfCMS, 2003).
- The National Service Framework for Children provides standards for services to apply nationally and locally to promote social inclusion, including standards for equipment services, housing and adaptations, and special needs transport. In particular, targets have been set to increase uptake of a Carers Special Grant by 2006 and to improve the life chances of all children.
- The *Integrated Community Equipment Services Initiative* has set a framework for the integration and improvement of community equipment and mobility services enabling disabled children to get out and about with greater ease (DH, 2001a).
- The Modernisation Agency has established a collaborative programme to support improvement in wheelchair services for disabled children (www.modern.nhs.uk).
- The Department for Education and Skills (DfES) Pathfinder scheme supports initiatives to improve transport services for disabled young people.
- The Special Education Needs and Disability Act (2001), the Special Education Needs Code of Practice and the Special Educational Needs Action Programme (DfES, 2001; 2003) all promote the inclusion of disabled children – and together with
- the White Paper, *Valuing People*, sets out an expectation that all local services will introduce person-centred planning for all young people moving from children's to adult services. It also requires Learning Disability Partnership Boards to identify a member with lead responsibility for transition issues, who will work with the Connexions service to ensure effective joint working and continued inclusion of the disabled child into adulthood (DH, 2001b).

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- support and monitoring
- training
- reviews
- making a Family Link supporters link
- insurance
- health and safety
- equipment and transport
- family link supporter's checklist
- medication
- HIV/AIDS statement
- standard hygiene procedure
- principles for working with children concerning care and control
- child protection procedures
- allegations against Family Link supporters
- guidelines on intimate care
- what to do in a crisis
- complaints procedure
- job description and person specification.

Contact: Somerset Inclusion Partnership, 34 Wellington Road, Taunton TA1 5AW.

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Policy initiatives concerning the development of a children's workforce:

- the Health Act (1999) includes flexibilities that allow agencies to make jointly funded appointments
- the Green Paper *Every Child Matters* (DH, 2003c) provides specific guidance on the issues involved in staffing children's services
- the National Service Framework for Children (DfES, DH, 2003 a-e) makes recommendations on recruitment and retention of staff
- the Audit Commission Report *Recruitment and Retention – A Public Service Workforce for the 21st Century* provides guidance on the recruitment, retention and development of staff skills (Audit Commission, 2002a)
- the NHS has published a National Workforce Competence Framework for Children's Services (www.skillsforhealth.org.uk)
- the Royal College of Nursing has published guidance entitled *Services for Children and Young People: Preparing Nurses for Future Roles* (RCN, 2004). Ring RCN Direct on 0845 772 6100, quoting publication code 002 454.

Royal Liverpool Children's Hospital NHS Trust Carer Education Programme (includes clinical guidelines):

- tracheostomy and stoma care
- suction
- ventilator use and maintenance
- oxygen dependency
- gastrostomy care and feeding
- tube feeding
- medications including administration
- lone worker policy.

Download from www.longtermventilation.nhs.uk

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Bath and North East Somerset Primary Care Trust/Lifetime Service. *Example of a Risk Assessment: Electromechanical Equipment in the Domestic Home*. Download from www.longtermventilation.nhs.uk

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Clinovia. *Quality Management Template*. Download from www.longtermventilation.nhs.uk

Clinovia/Thain, A. *Managing Risk in the Provision of Complex Care in the Home. PowerPoint Presentation*. Download from www.longtermventilation.nhs.uk

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Health and Safety Executive. *COSHH: A Brief Guide to the Regulations: What you need to know about the Control of Substances Hazardous to Health Regulations 2002 – INDG 136 (rev2)*. Download from www.hse.gov.uk/pubns/indg136.pdf

Health and Safety Executive. *Five Steps to Risk Assessment – INDG 163 (rev1)*. Download from www.hse.gov.uk/pubns/indg163.pdf

Health and Safety Executive. *A Guide to Risk Assessment Requirements – INDG 218*. Download from www.hse.gov.uk/pubns/indg218.pdf

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Materials are currently in development in relation to disability and safeguarding children, which will be available from the Council for Disabled Children in 2005.

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E) Key working, inter-agency and multi-agency working

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Department of Health (1998a) *Partnership in Action (New Opportunities for Joint Working Between Health and Social Services)*. Department of Health, London. To download follow links to the publications library from www.dh.gov.uk

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www.teachernet.gov.uk/wholeschool/healthandsafety/medical is a website that provides guidance on managing pupils with medical needs in school.

G) Housing, equipment and adaptations

Audit Commission (2002c) *Fully Equipped: The Provision of Equipment to Older or Disabled People by the NHS and Social Services in England and Wales*. Audit Commission, London. Download from www.audit-commission.gov.uk

Audit Commission (2002d) *Procurement and Supply: A Review of National Findings*. Audit Commission, London. Download from www.audit-commission.gov.uk

Benefit information can be obtained from the Department of Work and Pensions website: <http://www.dwp.gov.uk/>

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The Carers and Disabled Children Act (2000). HMSO, London. www.hmso.gov.uk/acts/acts2000

The Carers (Recognition and Services) Act (2000). HMSO, London. www.hmso.gov.uk/acts/acts2000

The Carers and Equal Opportunities Act (2004). HMSO, London. www.hmso.gov.uk/acts/acts2004

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l) Clinical guidelines

Barnardo's Family Link Somerset. Protocol for the training of carers and sessional workers in the clinical needs of long-term ventilated children. Including clinical protocols on:

- support and monitoring
- training
- reviews
- making a Family Link supporters link
- insurance
- health and safety
- equipment and transport
- family link supporter's checklist
- medication
- HIV/AIDS statement
- standard hygiene procedure
- principles for working with children concerning care and control
- child protection procedures
- allegations against Family Link supporters
- guidelines on intimate care
- what to do in a crisis
- complaints procedure
- job description and person specification.

Contact: Somerset Inclusion Partnership, 34 Wellington Road, Taunton TA1 5AW.

Newham Primary Care Trust/Clinovia. Clinical Guidelines:

- use of a skin-level mini-feeding tube
- replacement of a minitube
- use of a PEG
- administration of a bolus/gravity feed via a gastrostomy feeding tube
- administration of a continuous feed via a gastrostomy feeding tube
- dealing with complications while tube feeding
- management of children with tracheostomies
- suctioning the tracheostomy tube
- care of the tracheostomy site
- changing a bivona tracheostomy tube
- management of a blocked tracheostomy tube
- cleaning a bivona tracheostomy tube
- use of a sidestream nebuliser
- taking a child out of a ward or home environment for recreational activities
- ensuring a child's safety during outings
- checklist to go on outings
- changing ventilator tubings
- assembling a BiPAP/CPAP circuit for use with Fisher Paykel humidifier
- assembling the ventilator circuit without a Fisher Paykel humidifier
- use of heat moisture exchangers
- care of the sealed lead-acid battery.

Download from www.longtermventilation.co.uk

Royal Liverpool Children's Hospital NHS Trust Carer Education Programme (includes clinical guidelines):

- tracheostomy and stoma care
- suction
- ventilator use and maintenance
- oxygen dependency
- gastrostomy care and feeding
- tube feeding

- medications including administration
- lone worker policy.

Download from www.longtermventilation.nhs.uk

Transitional Care Unit, The Hospital for Sick Children, Great Ormond Street, London (2004). Clinical guidelines:

- application of medications by the associate carer
- taking the ventilated child out of the home environment
- ensuring a child's safety during outings
- care of the tracheostomy site
- changing a tracheostomy
- suctioning the tracheostomy tube
- management of a blocked tracheostomy tube
- use of a re-breathing bag for the CPAP/BiPAP assisted patient
- changing ventilator tubing
- new BiPAP circuit set up
- changing the BiPAP system into a mobile ventilator
- use of a Mic-Key skin level feeding tube
- administration of a bolus/gravity feed via a Mic-Key skin level feeding tube
- administration of a continuous feed via a Mic-Key skin level feeding tube
- power failure at home
- what to do in the event of: equipment failure, medical queries, nursing queries, acute emergency.

Download from www.longtermventilation.nhs.uk

University Hospital of North Staffordshire NHS Trust. *Protocol for the Transfer of the Long-term Ventilated Child from the Paediatric Intensive Care Unit (PICU) to Places of Education, Entertainment or Home Environment, Returning to PICU.* Draft 2. Download from www.longtermventilation.nhs.uk

J) Medical/self-management and follow-up

American Thoracic Society (1999) Idiopathic congenital central hypoventilation syndrome. Diagnosis and management, *American Journal of Respiratory and Critical Care Medicine* 160: 368–373.

Contact a Family (2004) *Working with Families Affected by Disability or Health Conditions from Pregnancy to Preschool*. A support pack to provide health professionals with practical suggestions on how best to communicate information and offer support to parents. Download from www.cafamily.org.uk/HealthSupportPack.pdf

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Fleming, P (2004) *What is Really Needed in Monitoring Children on Long-term Ventilation?* PowerPoint presentation. Download from www.longtermventilation.nhs.uk

Great Ormond Street Hospital for Children NHS Trust (2001) *Living with a Tracheostomy: Information for Families*. Great Ormond Street NHS Trust, London. Contact the Transitional Care Unit, Great Ormond Street Children's Hospital NHS Trust, Great Ormond Street, London WC1N 3JH.

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Vanderlaan, M, Holbrook, CR, Wang, M, Tuell, A, Gozal, D (2004) Epidemiological Survey of 196 Patients with Congenital Central Hypoventilation Syndrome, *Pediatric Pulmonology* 37: 217–229.

K) Transition

Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) (2001) *Palliative Care for Young People aged 13 – 24: A joint report by ACT, National Council for Hospice and Specialist Palliative Care and Scottish Partnership Agency for Palliative and Cancer Care*. ACT, Bristol.

Connexions (2004) Seven Principles for Inclusive Transition Planning. Download from www.connexions.gov.uk

Council For Disabled Children (December 2004) *Transition Newsletter. Getting A Life: Information for Everyone Working with and for Disabled Children in Transition from Childhood to Adulthood*. www.ncb.org.uk/cdc

Department for Education and Skills (2004b) *Future Positives*. Tool kit for local authorities in the development of effective and joined-up services which support young disabled children as they leave the 'looked-after' system. Email dfes@prolog.uk.com, quoting reference DfES/0880/2004.

Department of Health (2001b) *Valuing People. A New Strategy for Learning Difficulties for the 21st Century*. The Stationery Office, London.

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Nora Fry Research Centre, North Somerset People First and the Home Farm Trust (2004) *The Road Ahead*. Download from www.scie.org.uk/publications/tra/

O'Sullivan, T (2003) The Transition of Young Adults with Disability: a Study of the Effectiveness of Inter-agency Transition Planning. MCH 13–24. Download from www.dh.gov.uk/PolicyAndGuidance/ResearchAndDevelopment

Royal College of Nursing (2004) *Guidance on Adolescent Transition. Part 1: an Overview of the Issues to Consider when Planning Transition Services. Part 2: a Practical Framework for Working with Young People at each of the Major Phases of Adolescence*. Download at www.rcn.org.uk/members/publications/ or order from RCN Direct on 0845 772 6100, quoting publication code 002 313.

Royal College of Paediatrics and Child Health (2003) *Bridging the Gaps: Health Care for Adolescents*. RCPCH, London.

Suris, J, Michaud, P, Viner, R (2004) The adolescent with a chronic condition. Part I: developmental issues, *Archives of Disease in Childhood* 89(10): 938–942.

Transition Information Network. The network aims to improve the experience of disabled young people's transition to adulthood. A full resource list on transition is available from Lucia Winters at the Council for Disabled Children: lwinters@ncb.org.uk, website www.myfuturechoices.org.uk

Viner, R (1999) Transition from paediatric care to adult care: bridging the gaps or passing the buck?, *Archives of Disease in Childhood* 81: 271–275.

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L) Economic issues

Direct Payments

Carlin, J, Lenehan, C (2004) *Direct Experience. A Guide for Councils on the Implementation of Direct Payments in Children's Services*. Available from www.ncb.org.uk; contact Maria Bremmers, mbremmers@ncb.org.uk

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Department of Health (1999d) *Direct Payments: Cash for Services*. Information video. Department of Health, London.

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Parker, G, Bhakta, P, Lovett, C, Paisley, S, Olsen, R, Turner, D, Young, B (2002) A systematic review of the costs and effectiveness of different models of paediatric homecare, *Health Technology Assessment* (6) 35.

Scope. *My Money, My Way: a Young Person's Guide to Direct Payments*. Download from www.scope.org.uk/issues/directpayments, email publications@scope.org.uk

Costing packages of care

Noyes, J (2004) *Evaluation of Health and Social Care Provision for Ventilator-dependent Children in the UK*. PhD thesis, University of York. Contains examples of a range of costed packages of care. See www.longtermventilation.nhs.uk for an abridged version.

Personal Social Services Research Unit. Annual Compendium of Unit Costs for Health and Social Care. Download from www.pssru.ac.uk. The 2004 edition can also be downloaded from www.longtermventilation.nhs.uk

M) Social inclusion, involving children and their families, expert patients and short breaks

Boosefeld, B (2004) *Paediatric Complex Care: a Resource Guide for Parents and Carers* (unpublished), including:

- discharge planning and expectations
- respiration
- respiratory assessment
- tracheostomy
- mechanical ventilation
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dependent children, *Journal of Clinical Nursing* 8: 440–450.

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York Publishing Services, York.

West, S (2000) *Just a Shadow. A Review of Support for Fathers of Children with Disabilities*. Contact the Handsel Trust
on 0121 373 2747, email handsel.trust@virgin.net

Useful contacts

Ability Magazine (British Computer Society)

John Lamb Media Ltd
Dairy Cottages, Wolterton
Norfolk NR11 7LX
Tel: 01263 768572
Web: <http://www.abilitymagazine.org.uk/>

Access to Communication and Technology (ACT)

Oak Tree Lane Centre
91 Oak Tree Lane
Selly Oak, Birmingham
West Midlands B29 6JA
Tel: 0121 627 8235
Web: <http://www.wmrc.nhs.uk/act/>

ACE Centre Advisory Trust

92 Windmill Road
Headington
Oxford OX3 7DR
Tel: 01865 759800
Web: <http://www.ace-centre.org.uk/acemain.asp>

The ACE Centre-North

Units 11 & 12, Gatehead Business Park
Delph
Saddleworth OL3 5DE
Tel: 01457 829444
Web: <http://www.ace-north.org.uk/>

ACT: Association for Children with Life Threatening Conditions

Orchard House
Orchard Lane
Bristol BS1 5DT
Tel: 0117 922 1556
Email: info@act.org.uk
Web: <http://www.act.org.uk>

Advisory Centre for Education

1C Aberdeen Studios
22 Highbury Grove
London N5 2DQ
General Office Number (Monday–Friday 9.30am–5.30pm): 020 7354 8318 or 020 7704 3370
General Advice Line (Monday–Friday 2–5pm): FREEPHONE 0808 800 5793
Web: <http://www.ace-ed.org.uk/>

Aid for Children with Tracheostomies

Tel: 01823 698398

Email: support@actfortrachykids.com

Web: <http://www.actfortrachykids.com>

Ann Craft Trust (formerly NAPSAC)

Centre for Social Work

University of Nottingham

University Park

Nottingham NG7 2RD

Tel: 0115 951 5400 or 0115 846 6334

Email: information@anncrafttrust.org

Web: <http://www.anncrafttrust.org/>

ASC: Advice, Advocacy and Representation Service for Children

1–3 Greengate

Salford M3 7NN

Tel: 01608 398442

ASC (Action for Sick Children)

ASC HEAD OFFICE

Action for Sick Children,

National Children's Bureau,

8 Wakley Street,

London EC1V 7QE

Tel: 020 7843 6444

ASC MIDLANDS

Action for Sick Children

Midlands Office

No 3, Abbey Business Centre

Keats Lane, Earl Shilton

Leicestershire LE9 7DQ

Tel: 01455 845600

ASC SCOTLAND

Action for Sick Children (Scotland)

172 Leith Walk

Edinburgh EH6 5EA

Tel: 0131 553 6553

ASC WALES

A.W.C.H (Wales)

31 Penyrheol Drive

Sketty, Swansea SA2 9JT

Tel: 01792 205227

Web: <http://www.actionforsickchildren.org/>

Assistive Communication Aids Centres (ACS)

Communication Aid Centre
Speech and Language Therapy Department
Frenchay Hospital
Bristol BS16 1LE
Tel. 0117 975 3946
Email: cacfrenchay@north-bristol.swest.nhs.uk

Communication Aid Centre
2nd Floor, North Wing
Charing Cross Hospital
Fulham Palace Road
London, W6 8RF
Email: acs@rivernet.org.uk

Association for All Speech Impaired Children (AFASIC)

2nd Floor
50–52 Great Sutton Street
London EC1V 0DJ
Tel (administration): 020 7490 9410
Email: info@afasic.org.uk
Web: <http://www.afasic.org.uk/>

Augmentative Communication Service

Wolfson Centre
Mecklenburgh Square
London WC1N 2AP
Tel: 020 7837 7618
Email: k.price@ich.ucl.ac.uk

Barnardo's (Head Office)

Tanners Lane
Barkingside, Ilford
Essex IG6 1QG
Tel: 020 8550 8822

The CALL Centre (Communication Aids in Language and Learning)

University of Edinburgh
Paterson's Land, Holyrood Road
Edinburgh EH8 8AQ
Tel: 0131 651 6235/6236
Email: call.centre@ed.ac.uk
Web: <http://callcentre.education.ed.ac.uk/>

Care Co-ordination Network UK

Social Policy Research Unit
University of York
Heslington
York YO10 5DD
Tel: 01904 321959
Email: info@ccnuk.org.uk
Web: <http://www.ccnuk.org.uk>

Carers UK

20–25 Glasshouse Yard
London EC1A 4JT
Tel: 020 7490 8818
Web: <http://www.carersuk.org/>

CENMAC (Centre for Micro-Assisted Communication)

Charlton School
Charlton Park Road
London SE7 8JB
Tel: 020 8854 1019
Email: mail@cenmac.com
Web: <http://www.cenmac.com/>

Chailey Heritage Rehabilitation Engineering Unit

North Chailey
Lewes
Sussex BN8 4EF
Tel: 01825 722112 ext 210

Child-to-Child Trust

Institute of Education
20 Bedford Way
London WC1H 0AL
Tel: 020 7612 6649
Email: ccenquiries@ioe.ac.uk
Web: <http://www.child-to-child.org>

Childhood Research and Policy Centre

Social Sciences Research Unit
18 Woburn Square
London WC1H 0NS
Tel: 020 7612 6397
Email: ssru@ioe.ac.uk (please indicate: for the attention of the CRPC)
Web: <http://www.ioe.ac.uk/ssru/crpc.html>

Childline

Freepost NATN1111

London E1 6BR

Tel: 0800 1111

Web: <http://www.childline.org.uk/>

Children's Rights Alliance for England

Children's Rights Alliance, Joint National Co-ordinators

94 White Lion Street

London N1 9PF

Tel: 020 7278 8222

Email: info@crights.org.uk

Web: <http://www.crights.org.uk>

Christopher Reeve Paralysis Foundation

500 Morris Avenue

Springfield, NJ

USA

Web: <http://www.christopherreeve.org/>

College of Occupational Therapists

106–114 Borough High Street

London SE1 1LB

Tel: 020 7357 6480

Web: <http://www.cot.co.uk>

Communicate

The Lodge, Regional Rehabilitation Centre

Hunters Road

Newcastle upon Tyne NE2 4NR

Tel: 0191 219 5640

Email: communicate@nhs.net

Web: www.communicate-nhs.com

Communication Advice Centre

Greenpark Healthcare Trust

Musgrave Park Hospital, Stockmans Lane

Belfast BT9 7JB

Tel: 028 9066 9501

Email: hilary.robinson@greenpark.n-i.nhs.uk

Communication Aids Centre

Rookwood Hospital

Fairwater Road, Llandaff

Cardiff CF5 2YN

Tel: 029 2031 3956

Communication Clinic

Newcomen Centre, Guy's Hospital
St Thomas' Street
London SE1 9RT
Tel: 020 7955 5000 ext 3862

Communication Matters

c/o The ACE Centre
92 Windmill Road
Oxford OX3 7DR
Tel: 0845 456 8211
Web: <http://www.communicationmatters.org.uk/>

Congenital Central Hypoventilation Syndrome Family Support Network

71 Maple Street
Oneonta
NY 13820, USA
Email: VanderlaanM@Hartwick.Edu
Web: <http://www.cchsnetwork.org/>

CCHS Support Group

24 Larners Road
Toftwood
Dereham NR19 1LE
Tel: 01362 696509
email: cchssupp@hotmail.com

Contact a Family

209–211 City Road
London EC1V 1JN
Tel: 020 7608 8700
Helpline for parents and families 0808 808 3555 or Textphone 0808 808 3556
Email: info@cafamily.org.uk
Web: <http://www.cafamily.org.uk/index.html>

The Council for Disabled Children

8 Wakley Street
London EC1V 7QE
Tel: 020 7843 1900
Web: <http://www.ncb.org.uk/cdc/>

Department for Education and Skills

Web: <http://www.dfes.gov.uk>

Department of Health

Web: <http://www.dh.gov.uk>

Disabled Living Foundation

380–384 Harrow Road

London W9 2HU

Tel: 020 7289 6111 (Monday–Friday 9am–5pm)

Helpline: 0845 130 9177 (Monday–Friday 10.00am–1.00pm)

Web: <http://www.dlf.org.uk>

Family Fund Trust

Rowntree Wharf

PO Box 50

York YO1 9ZX

Email: info@familyfund.org.uk

Web: <http://www.familyfundtrust.org.uk/>

International Ventilator Users Network

4207 Lindell Boulevard #110

Saint Louis

Missouri 63108-2915, USA

Email: ventinfo@post-polio.org

Web: <http://www.post-polio.org/ivun>

Joseph Rowntree Foundation

The Homestead

40 Water End

York YO30 6WP

Tel: 01904 629241

Web: <http://www.jrf.org.uk>

keycom plc

University Court

Staffordshire Technology Park

Stafford ST18 0ES

Tel: 01785 717777

Web: <http://www.keycom.co.uk/>

The Lifetime Service

Child Health Department

Bath and North East Somerset Primary Care Trust

Bath NHS House, Newbridge Hill

Bath BA1 3QE

Tel: 01225 731624

Email: lifetime@banes-pct.nhs.uk

Mary Marlborough Specialist Disability Service

Mary Marlborough Centre, Communication Aids

Windmill Road, Headington

Oxford OX3 7LD

Tel: 01865 227 600

NALC (National Association of Laryngectomee Clubs)

Ground Floor, 6 Rickett Street
London SW6 1RU
Tel: 020 7381 9993
Web: <http://www.nalc.uk.com/>

NAPSAC see Ann Craft Trust

National Association of Hospital Play Staff

Email: tina.clegg@uhl-tr.nhs.uk
Web: <http://www.nahps.org.uk/>

National Federation of Access Centres

South West Regional ACCESS Centre, Disability ASSIST Service
University of Plymouth, Drake Circus
Plymouth PL4 8AA
Tel: 01752 232696
Email: M.M.Kemp@plymouth.ac.uk

NHS Direct (England and Wales)

NHS helpline: 0845 46 47
Web: <http://www.nhsdirect.nhs.uk/>

NHS Helpline (Scotland)

Tel: 0800 22 44 88 (8am–10pm)
Web: <http://www.show.scot.nhs.uk/public/publicindex.htm>

Ombudspeople

The Health Service Ombudsman England

11th Floor, Millbank Tower
Millbank
London SW1P 4QP
Tel: 0845 015 4033
Email: OHSC.Enquiries@ombudsman.gsi.gov.uk
Web: www.ombudsman.org.uk

The Health Service Ombudsman Wales

Fifth Floor, Capital Tower
Greyfriars Road
Cardiff CF10 3AG
Tel: 0845 601 0987
Email: WHSC.Enquiries@ombudsman.gsi.gov.uk

The Northern Ireland Ombudsman

The Ombudsman's Office, Progressive House
33 Wellington Place
Belfast
Tel: 0800 34 34 24 or 028 9023 3821
Email: ombudsman@ni-ombudsman.org.uk
Web: <http://www.ni-ombudsman.org.uk/ombadd.htm>

Scottish Public Services Ombudsman

4 Melville Street
Edinburgh EH3 7NS
Tel: 0870 011 5378
Email: enquiries@scottishombudsman.org.uk
Web: www.scottishombudsman.org.uk

The Local Government Ombudsmen: England

Millbank Tower
Millbank
London SW1P 4QP
Tel: 020 7217 4620 or 0845 602 1983

Beverley House
17 Shipton Road
York YO30 5FZ
Tel: 01904 380200

2 The Oaks
Westwood Way
Westwood Business Park
Coventry CV4 8JB
Tel: 024 7682 0000

See website for details of areas covered by each office: www.lgo.org.uk

The Local Government Ombudsman for Wales

Derwen House, Court Road
Bridgend CF31 1BN
Tel: 01656 661325
Email: enquiries@ombudsman-wales.org
Web: <http://www.ombudsman-wales.org/>

Outsiders Sex and Disability Helpline

Dr Tuppy Owens
BCM Box Lovely
London WC1N 3XX (enclose SAE)
Tel: 020 7499 3527 (11am–7pm)
Email: outsiders@clara.co.uk
Web: <http://www.outsiders.org.uk/>

ParentAbility

National Childbirth Trust
Alexandra House
Oldham Terrace
London W3 6NH
Tel: 020 8992 2616

Royal Institute of British Architects

66 Portland Place
London W1B 1AD
Tel 020 7580 5533
Email: info@inst.riba.org
Web: <http://www.riba.org/>

Scottish Centre of Technology for the Communication Impaired (SCTCI)

Westmarc, Southern General Hospital
1345 Govan Road
Glasgow G51 4TF
Tel: 0141 201 2619
Email: sctci@sgh.scot.nhs.uk

Sleep Disordered Breathing & Chronic Respiratory Failure Research Group

c/o Dr Colin Wallis
Great Ormond Street Hospital for Children NHS Trust
Great Ormond Street
London WC1N 3JH
Email: c.wallis@ich.ucl.ac.uk

Social Policy Research Unit

The University of York
Heslington
York YO10 5DD
Web: <http://www.york.ac.uk/inst/spru/>

Spinal Injuries Association

Acorn House
387–391 Midsummer Boulevard
Milton Keynes MK9 3HP
Tel: 0845 678 6633
Email: sia@spinal.co.uk
Web: <http://www.spinal.co.uk>

TASSCC (Technological Assessment and Support Service for Children and the Curriculum)

Summerhill Centre

Stronsay Drive

Aberdeen AB15 6JA

Tel: 01224 346127

Email: tasscc@aberdeencity.gov.uk

Web: <http://www.aberdeen-education.org.uk/tasscc/>

Whizz-kidz

1 Warwick Row

London SW1E 5ER

Tel: 020 7233 6600

Email: info@whizz-kidz.org.uk

Wired for Health (health information for schools and education professionals)

Web: <http://www.wiredforhealth.gov.uk>

The Who Cares? Trust

Kemp House

152–160 City Road

London EC1V 2NP

Tel: 020 7251 3117

Email: mailbox@thewhocarestrust.org.uk

Web: <http://www.thewhocarestrust.org.uk>

The focus of this guidance is on children who require long-term ventilation. The guidance has been compiled to assist multi-agency commissioners, managers and practitioners working in both statutory, voluntary and the private sectors improve important areas of practice such as discharge from hospital, and the experience of community support by children and young people requiring long-term ventilation. The content will also be of interest to parents and young people who use assisted ventilation.

The guidance contains five sections:

1. Core principles underpinning the organisation and delivery of multi-agency care
2. The exemplar outlining the care pathway for the long-term ventilated child
3. Hints, tips and tools for adapting and using the Care Pathway locally
4. Bibliographies of references and best practice guidance, and
5. A list of useful contacts

