



# **NHS at Home: Community Children's Nursing Services**

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# **NHS at Home: Community Children's Nursing Services**

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# Foreword

This document sets out the findings of a Department of Health project aimed at identifying and sharing local good practice in community children's nursing (CCN) services. It illustrates how CCN is a key component of community children's services, and demonstrates the contribution it can make to the future outcomes of integrated children's services.

It will be of interest to commissioners and providers of children's services, in particular to inform Quality, Innovation, Productivity and Prevention (QIPP) plans to reduce hospitalisation, and should be seen alongside the requirement set out in paragraph 4.34 of the *Operating Framework for the NHS in England 2011/12* for 24/7 community services to improve end-of-life care, and the *Palliative Care Funding Review Interim Report* (December 2010).

# Executive summary

Currently, few local community children's nursing (CCN) services are able to meet the needs of all ill and disabled children and young people, who have been divided into four groups.

These are:

- children with acute and short-term conditions;
- children with long-term conditions;
- children with disabilities and complex conditions, including those requiring continuing care and neonates; and
- children with life-limiting and life-threatening illness, including those requiring palliative and end-of-life care.

CCN services are the bedrock of the pathways of care for these groups of children.

Research undertaken by the University of Central Lancashire and the University of the West of England for the Department of Health<sup>1</sup> described the importance of reliable, accessible expert CCN provision to families to enable them to care for their child at home and recorded the families' deep frustration at the patchy, fragmented postcode lottery provision of services that currently exists.

A "comprehensive" service should be the bedrock of wider out of hospital services for ill and disabled children and requires staff with the skills to cater to the needs of all four groups of children and young people and with the flexibility to adapt services when children move from one group to another.

A comprehensive service requires a "critical mass" of staff, which in turn improves the sustainability, accessibility and efficiency of the service. In some areas this could be achieved by bringing together staff from existing disparate services.

Key messages – what works for a safe, sustainable service – and examples of how CCN services are contributing to the care pathways of the four groups of children are set out in this document.

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<sup>1</sup> Carter B, Coad J, Goodenough I et al. (2009) *Community Children's Nursing in England: An appreciative review of CCNs*. Department of Health in collaboration with the University of Lancashire and the University of the West of England.

# 1. Current provision for out of hospital care for children and young people

To improve the experiences of children, young people and their families, care needs to be delivered across integrated pathways of services: primary, secondary and in some cases tertiary care; transition into adult services; and health, children's social care, education and housing services.

To ensure that the needs of all ill and disabled children are met, four groups of children and young people have been identified as needing services (described later in this document). These are:

- children with acute and short-term conditions;
- children with long-term conditions;
- children with disabilities and complex conditions, including those requiring continuing care and neonates; and
- children with life-limiting and life-threatening illness, including those requiring palliative and end-of-life care.

Community children's nursing (CCN) services are the bedrock of the pathways of care for these groups of children.

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<sup>2</sup> Ibid.

## 2. Outcomes/achievements

The needs of children, young people and their families will be met when:

- parents can rely on services that are accessible, equitable, comprehensive, sustainable and flexible for all children and young people with a nursing need regardless of geography or diagnosis;
- there is no discrimination on the grounds of race, disability, gender, age, sexual orientation, religion or belief – this does not preclude developing interventions targeted at particular groups of children and young people;
- parents are able to put being parents first and healthcare providers second and are confident they have the skills to care for their child through a genuine partnership with health professionals. Implicit in this is that parents are kept fully informed about their child's diagnosis, complications and what to look for;
- advocacy is offered where the views of the child/young person or their parents are different, or where they need someone else to speak on their behalf or represent them;
- parents experience a co-ordinated seamless service that is centred on parental choice and decision-making, personalised to the individual child and family, and promoting independence and quality of life;
- children and young people are admitted to hospital or stay in hospital only when it is clinically unsafe to care for them in the community. Timely arrangements for care packages will achieve this, as proposed in the *National Framework for Children and Young People's Continuing Care* (March 2010);
- children in need of a comprehensive care package will experience fewer hospital admissions and fewer visits to accident and emergency departments for crisis management;
- children with complex needs who are vulnerable to infection are protected from healthcare-acquired infection;
- families have reliable, simple and easy access to the resources required to provide optimal care for their child, allowing them to focus on caring for their child and spending more time being a family (for example, information, equipment); and
- there is genuine choice about end-of-life care, acknowledging the preferences of the child/young person and of the families.

### 3. Securing comprehensive, safe and sustainable services

Currently, few local CCN services are able to meet the needs of all ill and disabled children and young people in the four groups.

In a national survey of paediatric healthcare (the York study)<sup>3</sup> 103 of the 297 services that responded were categorised as “generic community children's nursing or home care teams”. The other services ranged from condition-specific services to day care, some of which were delivered by specialist CCN teams. It is difficult to ascertain the coverage of services across the country from this survey because not all trusts responded and because of the complexity of different providers and their geographical coverage; however, 99% of the generic CCN services that responded reported the area they served as “local”. Both the York and the Department of Health studies found primary care trusts (PCTs) that did not have services covering the whole of their area, usually for historical reasons.

The Department of Health and York projects found additional restrictions on services due to access being determined by criteria such as diagnosis, hospital consultant, address or GP registration. In the York study, 17% of services excluded children's access to care on area and 15% on condition. Further, 46% of the generic CCN services were reported as available only on weekdays.

An anecdotal report from the North of England described the provision of care for children and young people with cancer, listing the shortcomings in some areas including:

- extremely limited, if any, end-of-life care;
- no weekend or out-of-hours cover;
- no support for home chemotherapy;
- children not discharged for home antibiotics once afebrile and clinically stable; and
- most services cutting off at age 16 but adults' services having concerns about being suitably skilled for the 16–19 age group.

In the York study, 79.2% of respondents across all services stated a need for extended coverage, increased staffing and increased psychological support.

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<sup>3</sup> Cusworth L, Spiers G, Parker G, et al. (in press) Evaluating models of care closer to home for children and young people who are ill: main report. National Institute for Health Research Service Delivery and Organization programme; 2011.

A "comprehensive" service should be the bedrock of wider out of hospital services for ill and disabled children and requires staff with the skills to cater to the needs of all four groups of children and young people and with the flexibility to adapt services when children move from one group to another.

A comprehensive service requires a "critical mass" of staff, which in turn improves the sustainability, accessibility and efficiency of the service. In some areas this could be achieved by bringing together staff from existing disparate services.

Ill and disabled children and young people need, and may already be receiving, other services, such as those for special educational needs, and/or services provided by allied health professionals. It is therefore important to ensure that the development of a CCN service takes account of and works closely with other community health services for children, such as primary care, and the wider local multi-agency services. This should include identifying funding for access to community equipment for disabled children, as a lack of this equipment is a common reason for delayed discharge from acute settings.

Standard 6 of the *National Service Framework for Children, Young People and Maternity Services*<sup>4</sup> set out the need for CCN services to be part of children's community teams. The York University report suggested that services should be an integrated part of a co-located wider network of multi-agency child and family services that provide for children's existing and future needs and which ensure consistent, high-quality transitions between services (hospital and home; health/social care/education; and children's and adults' services).

## Models of service

Currently, services are provided predominantly by acute and community providers or as part of children's trusts. There are some examples of outreach provision from voluntary organisations: 'The voluntary sector brings a unique dimension to the provision of children's palliative care and usefully complements statutory provision.'<sup>5</sup>

The provider does not necessarily determine the base for the service, therefore CCN services can be provided by one organisation but based in a building belonging to a different organisation – for instance, a service provided by an acute provider might have staff co-located with community services and vice versa.

<sup>4</sup> Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services*.

<sup>5</sup> Department of Health (2008) *Better Care: Better Lives. Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions*.

Each model has its merits and whether or not the benefits are realised has more to do with local arrangements and ways of working than with organisational structures. Decisions about this need to be made locally. The important factor is that services are designed to focus on the needs of children and their families and are integrated at the point of delivery.

When acute providers deliver services, they include the potential benefits of enhancing closer working between hospital staff and the CCN team, providing easily accessible expertise and support from hospital-based paediatricians and specialist nurses. Opportunities for staff rotation between hospital and the community to improve skills and competencies may also be more easily achieved.

When community providers deliver services, they include the potential advantages of being based in an organisation that has more knowledge and understanding of the needs of staff working in the community. Co-location with community children's teams, such as community health, social care, preschool and school, can have great benefits in providing joined-up services for children with complex needs as well as the provision of training for short break care.

Organisations resulting in vertical integration offer an easier way of taking a pathway approach.

In some areas where the population is smaller, models that commission either the whole or part of the services across more than one geographical area may be most effective, particularly when delivering out-of-hours or specialist care. A network of more locally based services can also provide increased flexibility and improved opportunities for staff development, and will therefore enhance recruitment.

The following are examples of comprehensive services.

## Islington comprehensive service – teams within a team

The CCN service supplies registered children's nurses with a CCN qualification and/or experience to provide nursing care for children and young people at home with their families. The nurses are a readily accessible source of support, information and advice for families. The teams work with specific groups of children according to their clinical needs.

### Generalist CCN team, including asthma, allergy and eczema care pathways

This team sees children for direct nursing care either at home or in school/nursery and assists parents to provide treatment and to monitor the child's or young person's progress. The team often acts as lead professional for those with long-term conditions – and this makes up a significant proportion of the caseload (for example, cancer, respiratory conditions, metabolic disorders). The generalist team's nurses also manage acute short-term conditions to facilitate earlier discharge from hospital or to prevent admission (for example, wound care, intravenous antibiotics). Care pathways for children with asthma have been improved by interventions introduced by the nurses, including the development of the nurse-led eczema clinic where treatment is prescribed. Recently a community allergy nurse specialist post has been developed to work in partnership with the local hospital to improve the referral and care pathway for children with allergies.

### Complex continuing care team

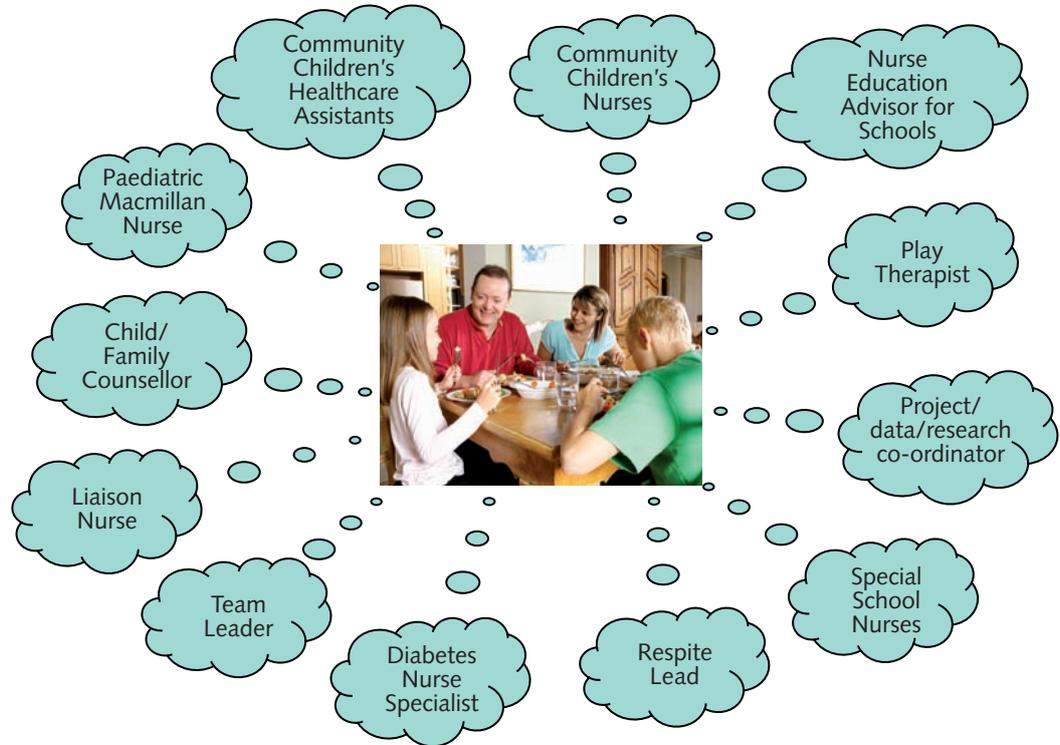
This team works in partnership with the family to co-ordinate and manage packages of nursing homecare for children and young people with complex continuing health needs who require technology and supportive care to remain at home (for example, tracheostomy with or without assisted ventilation). Care is provided by a team of community support workers specifically trained in individual children's care, supported by qualified nurses.

### Life Force team: paediatric palliative care and bereavement services

This team provides supportive care and clinical symptom management to children and young people with a life-limiting or life-threatening condition through to the end of life. It also provides bereavement support. It is a multidisciplinary team made up of a specialist nurse, play/youth specialist, respite nursery nurses, a paediatric palliative care consultant and a clinical psychologist. The team was established in September 2003 with three-year funding from the New Opportunities Fund; it has been funded from the mainstream budget since 2006.

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## Rotherham community children's nursing team



The Rotherham complex health needs team operates a needs-led model of service delivery whereby personalised treatment and care can be provided at home or in any community setting. When necessary, the team also follows the child into hospital. Continuity is achieved when trusted, highly skilled team members, known to the child and family, are able to follow the child wherever they go.

The team is involved from recognition/diagnosis throughout the child's journey, including transition, and where required supports the family through bereavement. Child-/family-centred assessments, planning and care provision can be delivered at any time.

Where safe, appropriate and clinically indicated, the team provides interventions as an alternative to hospital and GP, thus minimising the distress and disruption to the child's day-to-day activities and enhancing the well-being of the whole family.

The team is flexible enough to meet the changing needs of the child and family, increasing support quickly during times of crisis, deterioration or at the end of life.

Collectively, the team has developed strength in knowledge, skills, resource flexibility and responsiveness. The provision of real alternatives and choice leads to positive outcomes and experiences for the whole family.

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## North Central London community children's nursing network

The purpose of the network is to ensure a more unified approach to the CCN service across five boroughs.

Benefits include:

- enhanced leadership of the teams;
- leadership development nurtured among the nurses through sharing of expertise at forums, seminars and conferences;
- sharing of specialist resources;
- shared use of expensive equipment;
- shared standards and clinical guidelines;
- a greater capacity for training, updating and developing competencies in key nursing skills across the sector;
- more evenly spread education and training of students; and
- shared provision of clinical supervision for all members of staff.

The recruitment and retention of community children's nurses is notably easier as the prospect of working for a network, with the associated benefits, rather than a traditional small CCN team is attractive.

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## Key messages

The following key messages underpinning the organisation and delivery of care at local level have been developed from the findings of the Department of Health study to help local commissioners and providers.

### Key messages – what works for a safe, sustainable service

- The development of the service is informed by a local vision for children's services developed and owned by an executive champion.
- Health and local authority partners commission a comprehensive CCN service as part of wider health and multi-agency children's services, to enable ill and disabled children achieve the five outcomes of Every Child Matters.
- The service commissioned is informed by the joint strategic needs assessment and the Children and Young People's Plan/Joint Health and Wellbeing Strategy (subject to Parliamentary approval), the views of children, young people and their families and is flexible enough to allow personalisation and greater control by the child or young person and their family.

- The CCN service has a good working relationship with local GPs who play a crucial role in the communication, relationship building and management of protocols of care, referral pathways and out-of-hours care arrangements.
- The commissioned service is informed by clear, locally agreed pathways for the four groups of children set out below which clearly define the contribution of a CCN service required:
  - children with acute and short-term conditions;
  - children with long-term conditions;
  - children with disabilities and complex conditions, including those requiring continuing care and neonates; and
  - children with life-limiting and life-threatening illness, including those requiring palliative and end-of-life care.
- There is a single organisational structure responsible for delivering the comprehensive service led by registered community children's nurses, supported by assistant practitioners and support workers and with administrative support.
- The team has the knowledge, expertise and capability to lead and co-ordinate the delivery of services to babies, children and young people and their families in the community which are flexible and personalised to meet their identified health and well-being needs and are not restricted by diagnosis.
- The nursing service includes therapeutic play support for the child and any siblings where appropriate.
- The service provides 24/7 access to advice and support for families and carers and, in end-of-life care, 24-hour visiting as required. The findings suggest a service is needed to children at home 8am–10pm with telephone advice out of hours, by people who are knowledgeable about community children's services and the individual child, with the ability to make a home visit if necessary.
- The CCN service works closely with health and children's services colleagues to deliver a co-ordinated, cohesive service to children, young people and their families for example, with the health visiting team and early years and with the school nursing team and education colleagues, to facilitate the child's access to education.

- Nursing staff are able to assess a child's symptoms and recognise a sick or deteriorating child and to take first steps in the management of the child's condition, including referral to a GP, specialist nurse or hospital paediatrician as appropriate.
- The service includes nurses trained as nurse prescribers to prescribe medications for a child where appropriate.
- There is access to diagnosis-specific advice and guidance (for example, access to specialist nurses and community children's nurses who have a special interest or responsibility).
- There is access to community equipment to enable sustained home support.
- The service has the capacity to provide a reliable/sustainable care package for children who are technology dependent, to facilitate earlier discharge from hospital and enable them to lead as normal a life as possible.
- Clear protocols are in place to:
  - facilitate/support access to hospital care when necessary for children who have complex care needs and are normally cared for at home;
  - support hospital and community staff when such children require admission to hospital to ensure the child is looked after by safe competent staff in the hospital environment;
  - enable the community children's nurse to seek advice and to make referrals where appropriate to other members of the integrated team (for example, physiotherapists); and
  - develop local arrangements for transition into adult care services, with early involvement of the GP to ensure there is good, timely planning for the transition.

## 4. Supporting out of hospital care

This section takes each of the four groups of children and sets out local practice examples of the contribution of CCN services to the pathways of care.

### 4a. Children with acute and short-term conditions

**The contribution community children's nurses can make to pathways of care for children and young people with acute and short-term conditions.**

There are a number of roles community children's nurses can contribute to pathways of care for children and young people with acute and short-term conditions. These are divided into two sections:

- avoiding hospital admission; and
- enabling early discharge thereby reducing length of stay.

#### **Avoiding hospital admission**

##### *Following assessment by another health professional*

As part of the local pathway for urgent or emergency care, the CCN service can provide follow-up care and treatment, supported by appropriate protocols, to prevent the hospital admission of moderately ill children (for example, those with respiratory conditions or gastroenteritis).

##### *Advanced children's nurse practitioner role assessing the acutely ill child in a variety of settings to prevent hospital admission*

Advanced children's nurse practitioners who are skilled in assessing ill children, making diagnoses and ordering investigations and treatment, including prescribing medication, are able to provide services in a range of settings more accessible to families. This can be a vital part of the pathway in areas where traditional secondary care services are being consolidated on fewer sites.

One group who can benefit from this is single parents and parents isolated from their extended family, who seek advice when their children suffer relatively minor illnesses. Empowering them to manage these illnesses themselves reduces their dependency on the NHS. For example, walk-in centres providing assessment, advice and treatment enable parents to manage the illness at an early stage, thus preventing the need for attendance at accident and emergency departments or admission to hospital.

## Smithdown Children's NHS Walk-in Centre, Liverpool Community Health

Smithdown Children's NHS Walk-in Centre (SCWIC) is entirely nurse-led, with children's minor illness/injury assessment and management provided by a team of advanced paediatric nurse practitioners in collaboration with paediatric nurse practitioners and practitioner's assistants. There are X-ray facilities available Monday to Friday (diagnosis confirmed by consultant radiologists) and access to some off-site diagnostics that include haematology and microbiology.

A total of 16,316 children were seen in 2008/09 with attendances for 2009/10 forecast to increase by 10%.

Illness completion rates consistently exceed 85% and the minor illness/injury attendances in the children's accident and emergency department have seen only a minimal increase in sharp contrast to the steady increases in paediatric attendances nationally.

The centre provides acute services for children close to home; its success is evidenced by the illness completion rates and the marked growth in attendance figures. According to service users:

"It's a great centre to come to with children to be checked out. We are very lucky to have this facility and really appreciate it. Thanks."

"It's a wonderful centre and all staff are of highest quality and professionalism."

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### *Assessing a child who has a long-term condition or complex care needs to prevent hospital admission*

Parents of children who have long-term conditions or complex care needs value highly being able to call the community children's nurse when their child's condition changes due to an acute illness as an exacerbation or complication of an underlying condition. The nurse who is familiar with the child is able to assess in the home whether or not they need hospital admission, preventing unnecessary journeys to a surgery or hospital. Parents say that when their child is assessed by the GP or hospital staff they are more likely to be admitted to hospital as a default position because these staff are unfamiliar with the child's "normal" state.

"We would manage it by ringing the CCN first, then we would talk about what I should do."

"You really panic if it's after 10pm and she starts. I say, oh God please not now. We'll have to go to hospital. In the day I wouldn't – I'd ring [CCN's name]."

### **Enabling early discharge thereby reducing length of stay**

CCN services can not only prevent hospital admission for some children, but reduce the length of stay for those who need to be admitted. The UCLAN/UWE consultation recorded 16 examples of a child or young person coming home early (ranging from one to five days early in any one episode). Again, in one area, "acutely ill children could be assessed in the acute care situation and as appropriate, discharged home early to be followed up by a CCN. This was highly valued by the children and families. However, in other areas families frequently spoke of discharge being delayed until a CCN was available."

"The CCN comes to the hospital to see her [child]. As soon as she's in, the CCN puts her name down for having IVs at home so she only stays overnight."

"He can only be discharged from hospital if there is enough staff to take him home, so sometimes he has to wait until a slot comes up."

### **Lambeth, Lewisham and Southwark community children's nursing team**

The team delivers acute children's nursing care with the objective of cutting length of stay in hospital and reducing readmission rates. The service is provided 365 days a year as part of acute pathways of care agreed by the three boroughs' children's commissioners. These include:

- oncology;
- tracheostomy;
- home oxygen;
- intravenous antibiotics;
- wound care;
- enteral feeding; and
- overnight oxygen saturation studies.

Anyone, including families, can refer if the child has an acute nursing need. The team can deliver a service from the next day. For example, a child diagnosed with meningitis may be referred to the service to complete a course of intravenous antibiotics after having spent only 48 hours as an inpatient. The child will still be acutely unwell but the team works very closely with the acute unit and has a named paediatrician for the child whom they will liaise with if there are any concerns.

Benefits identified by the service include the child being cared for in a familiar environment, a reduction in the emotional trauma they and the family may experience and a highly skilled, motivated and competent workforce which is more likely to remain stable. In fact, the service has had no difficulty in recruiting, no post has been left vacant in the last five years and there is a very low turnover of staff.

Unit costs for acute care at home were found to be considerably cheaper than NHS tariffs for inpatient stays. When the service was reviewed in 2008 by an outside organisation, cost comparisons were looked at based on unit costs of the CCN service compared with NHS tariffs. Costs by pathway of care from the CCN service came in at between 30% and 50% cheaper than the cost for the care to be delivered in hospital.

Users of this service value it highly, with the most frequently reported reasons being "not having to go back to hospital" and "the nurses really knew their stuff". The children said they liked the nurses because "they were kind" and "they gave me stickers".

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### The children's acute nursing initiative team, Newcastle

The children's acute nursing initiative (CANI) team was created to facilitate much earlier hospital discharge for children and young people living in Newcastle with acute illnesses and exacerbations of chronic conditions. The service creates a "virtual ward in the community" so that children with stable conditions can be nursed safely at home. This significantly shortens admission periods and facilitates more "timely" discharge, thus reducing family stress and disruption and the economic impact of hospitalisation.

The objectives of the service are to:

- provide a high-quality, flexible and responsive service;
- shorten admission periods, and facilitate timely discharge;
- increase patient choice and offer care closer to home; and
- improve trust, efficiency and effectiveness.

Nursing care by the CANI team includes:

- further clinical monitoring, assessment and continued treatment;
- intravenous medication for a large number of conditions, up to three times a day;
- support and advice to reduce parental anxiety; and
- further education and information to empower parents to care for their child during the period of illness and recovery.

In the first year, the service has facilitated the early discharge of 335 children and freed up 2,318 acute bed days (1,372 days in cubicles).

The service won the *Health Service Journal* 2010 award for enhancing quality and efficiency in services for children and young people.

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An evaluation of the services provided by the CANI team, managed by Newcastle Hospitals NHS Foundation Trust, showed that during the fiscal year 2008–09, 274 patients were referred from the hospital to care within the home. This resulted in 1,996 potential bed/cubicle days saved, which is equivalent to £1.1 million in hospital costs. After accounting for CANI staffing and equipment costs, the potential saving to the trust amounted to £923,768.<sup>6</sup>

#### 4b. Children with long-term conditions

**The contribution community children's nurses can make to the pathways of care for children and young people with long-term conditions.**

##### Improved quality of life for children and young people

Children and young people want to get on and live as normal a life as possible; however, children with a long-term condition often experience frequent disruption to their everyday lives, especially absence from school for hospital appointments or due to an exacerbation of their condition.

Everyone has a different vision of what "normal life" is and personalisation of healthcare helps children and young people to meet their wider aims and needs. For example, by having access to a CCN service in collaboration with the school nursing team, a child can have an individual health plan. This enables them to learn how to manage their illness and its treatment, to recognise early signs

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<sup>6</sup> Willey E (2008) Proposal for continuation and expansion of current service (CANI team). Unpublished paper.

of exacerbation and know when to seek help. It also reduces the impact their condition may have on their ability to access the curriculum and participate fully in school life, becoming independent and achieving the five Every Child Matters outcomes.

Younger children often do not realise the person visiting them is a nurse, and they like the fact that seeing the nurse without wearing a uniform stops them from being "different". The nurse works with the school to ensure that care needs can be met in school; or, if the visit takes place at home that they return to their education and friends as soon as possible.

### Rotherham nurse education advisor role

The appointment of the nurse education advisor to Rotherham's CCN team was as a direct result of a child and parent request. Families wanted their children to be able to access school with the same ease as a well child. They wanted choices for mainstream and special school placement and they needed to be confident that their child would have their educational and medical needs competently met while at school.

There are currently 293 children in schools within the borough who, as a result, have been able to access school with relative ease. The nurse education advisor works closely with the school nurse, co-ordinating and developing an individual, personalised training package for local authority colleagues. Liaison with health, education and transport colleagues takes place in advance of admission and joint risk assessments are undertaken. A care plan is formulated, giving details of all care and intervention needed by the child as well as copies of jointly ratified procedures and emergency plans. The school identifies and allocates a small group of support staff who undergo training to enable them to provide care for the child in school. Healthcare assistants from within the team provide "in-reach" into school to deliver care and support to the child where needed until the training package is completed and full competency and confidence are achieved. Parallel services can be maintained for a period of up to three months. The school has access to the team's on-call service provided by the community children's nurses who deliver intervention, support and rapid response to children both in and out of the home. All the nurses have first contact practitioner skills and prescribing qualifications.

Feedback from children and families indicates that this approach has "given assurances" and "significantly improved continuity and quality of care".

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### **Nurse-led clinics for children with conditions such as eczema and constipation**

Community children's nurses are among the professionals who can deal with an increasing number of outpatient appointments for minor problems such as rashes and constipation as well as long-term conditions management for such conditions as diabetes and asthma which have been traditionally seen by consultant paediatricians in a hospital setting.

#### **Islington nurse consultant eczema clinic**

The nurse consultant in the CCN team set up a nurse-led eczema clinic based in two health centres in Islington PCT in 2006. The majority of children are referred to the clinic by GPs and health visitors, although parents and other professionals are also able to self-refer. The clinic has led to improved health outcomes for children with eczema through providing a seamless local community service for children. The nurse consultant refers to a dermatologist in secondary care only if the eczema cannot be adequately managed in the community. As a result, there is a more consistent approach to eczema support and education for families and greater compliance and understanding of the practical advice given. The nurse consultant has completed the nurse independent prescribing course which has greatly enhanced her autonomy in the management of children with eczema in the nurse-led clinic as she is able to complete the whole process of assessing, diagnosing and then prescribing. An important aspect of prescribing is checking the parents' understanding of how to use the emollients or topical steroids prescribed and being able to provide an explanation before writing a prescription.

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### **Ensuring specialist nurses' knowledge and skills are available to children with specific conditions such as diabetes, asthma, epilepsy, cystic fibrosis and cancer**

The numbers of children with any specific condition in a typical PCT are relatively small. Therefore nurse specialist roles tend to be hospital-based, providing outreach services across a wider geographical area. Having a CCN service that develops a range of individual "special interests" in addition to its generalist role, working in partnership with and supported by the appropriate nurse specialist, is an effective way of delivering a locally accessible service.

Depending on the size of the PCT and the condition, this may need to be a model where the community children's nurse with a special interest works across more than one PCT in partnership with the nurse specialist.

### **The cystic fibrosis clinical nurse specialist, Coventry**

The Coventry cystic fibrosis clinical nurse specialist works as part of the CCN team, with some generic CCN work to help cover the on-call service or colleagues' leave.

The cystic fibrosis clinic caters for 45 children from the Coventry and Warwickshire area, sharing care with the tertiary unit at Birmingham Children's Hospital. The role is based in Coventry and funded by Coventry PCT, but covers the area of two PCTs.

All care is managed and delivered by the local cystic fibrosis team, including inpatient care. The clinical nurse specialist role is community based, with home care being a driving principle, but it also has input into University Hospitals Coventry and Warwickshire (UHCW) outpatient service with strong in-reach to children having inpatient intravenous courses, and also facilitating discharge planning and the delivery of home intravenous therapy, working closely with the ward link nurses.

The cystic fibrosis clinical nurse specialist works with a community children's nurse from the Warwickshire PCT who has a special interest in cystic fibrosis, and the latter delivers much of the day-to-day, hands-on care. The team offers families the opportunity for the cystic fibrosis paediatrician and nurse to visit at home when the diagnosis is made or difficult issues need to be discussed. These visits may take place in the evening to allow working parents to be involved without the need to take time off work.

Home visits for respiratory assessment of acute exacerbations, intravenous therapy, flushing central venous access devices, aminoglycoside monitoring, glucose tolerance testing, on-going training and support are available to all families. The community focus ensures that care is planned to disrupt school and family life as little as possible.

When required, the cystic fibrosis clinical nurse specialist leads end-of-life care in collaboration with palliative care colleagues, ensuring that young people have the choice to be at home if they and the family wish it.

The plan for transition to adults' services is a different model from many, complicated by the fact that these services are delivered from Heartlands Hospital, Birmingham, with no local inpatient service. However, the adult-trained cystic fibrosis nurse is based within the CCN team. She carries a small generic paediatric caseload in addition to the adult cystic fibrosis caseload. There is cross cover between the paediatric and adult nurses for annual leave, sickness etc. This means that the young person and family will have known the adult nurse from diagnosis, making transition a much less traumatic process. When a new diagnosis occurs, it is helpful for the family to meet the adult nurse and understand that, in general, young people with cystic fibrosis have an improved prognosis; it helps them to believe in a future for their child.

The timing of transition is linked to the school year, with young people anticipating their first adult appointment in the school year following completion of year 11. The thinking behind this is that they and their peers will be moving into the sixth form, college or the workplace, and this happens irrespective of the maturity, size or well-being of the individual. Making the move to the adult clinic is part of the general move towards adulthood.

The first adult appointment takes place locally in the adult outpatients' department with the visiting Heartlands team, the cystic fibrosis paediatrician, and the local adult and paediatric cystic fibrosis nurses.

Young people continue to have local appointments with the visiting tertiary cystic fibrosis team while the paediatric team gradually withdraws.

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### South East Essex specialist services as part of the CCN team

In South East Essex PCT the asthma/allergy service has been integrated into the CCN team in order to provide 24-hour support for children requiring acute nursing care at home.

In addition, a paediatric Macmillan nurse is shared with the service in South West Essex.

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### Diabetes home care service, Birmingham Children's Hospital

The diabetes home care (DHC) unit at Birmingham Children's Hospital provides 24-hour care for children with diabetes in the form of home visits, routine monitoring and assessment of diabetes control at the outpatient clinic. It also offers support and education to healthcare professionals. The aim of the service was to reduce hospital admissions and increase home management at diagnosis. In 1984, the unit cared for 230 children with diabetes, which had increased to 400 by 2003.

The unit reported that, by 2003, the median proportion of newly diagnosed children totally managed at home was 43%.<sup>7</sup> In 2003, the readmission rate for existing hospital patients was two bed days per patient per year, compared with 0.2 bed days per DHC patient per year. Their evaluations showed that this resulted in a saving of 705 bed days per year, which could lead to potential hospital savings of £355,500, when costings of £500 per diabetic bed day (at 2003 prices) are taken into account.

### Better management of long-term conditions reducing hospitalisation

Keeping children out of hospital has many benefits, as has already been acknowledged.

The following quotes from parents illustrate their experience of the benefits of receiving a CCN service to reduce hospitalisation.

"In 2007/08 she had 14 hospital admissions lasting one day to five days. Since the CCN came, during 2009 she has had only two."

"Every three months she needs antibiotics as a precaution, now she has them at home. Every course of antibiotics lasts two weeks; this meant two weeks in hospital."

"Now the CCNs are doing the frusemide infusions – thank goodness – and this has stopped us having to go back into hospital every day for the past 10 weeks."

"I think the best thing is that you don't have to worry about taking her to hospital or to the GP surgery, where she could catch more infections. It feels like a mini-hospital at home. All in all this service keeps my child out of hospital and at home with me."

<sup>7</sup> McEvelly A, Kirk J (2005) Twenty years of a multidisciplinary paediatric diabetes home care unit. *Archives of Disease in Childhood* 90(4): 342–345.

In 2002/03, there were 21,840 hospital admissions for asthma in England for children aged under 15 years.<sup>8</sup>

The annual cost to the NHS of diagnosed asthma in childhood was estimated at £254 million and the annual cost of treating a young child with asthma was estimated at £181, at 2002 prices.<sup>9</sup>

Anti-asthma medications constitute a large proportion of all drugs prescribed in general practice and incur a cost to the NHS of more than £500 million per year.<sup>10</sup>

#### 4c. Children with disabilities and complex conditions, including those requiring continuing care and neonates

- A third of parents with a severely disabled child under two years old use more than three pieces of equipment daily to provide basic care.
- Four out of five 12–14-year-old severely disabled children need help with eating, washing, dressing and toileting.
- Spending less time in hospital and feeling less tired were some of the positive benefits of home ventilation reported by children and families.
- Research shows that higher quality, more flexible and better co-ordinated nurse-led home care can improve the quality of life and health of children who use ventilators.<sup>11</sup>
- Children with complex care needs are staying in hospital, often in paediatric intensive care beds, because of delays in funding and setting up packages of care in the home.<sup>12</sup>

**The contribution community children's nurses can make to the pathways of care for children and young people with disabilities and complex conditions, including continuing care needs.**

#### Enabling care at home – reducing length of stay and costs

The development of local CCN services enables commissioners to provide care for children at home, reducing extensive lengths of stay in hospital or placement in expensive residential care, thereby improving quality of life for children, young people and their families as well as yielding savings.

8 Hospital Episode Statistics 2002–03. NHS Information Centre.

9 National Asthma Campaign (2002) Starting as we mean to go on: An audit of children's asthma in the UK. *Asthma Journal* 8(2): special supplement.

10 Hoskins G, McCowan C, Neville RG, et al. (2000) Risk factors and costs associated with an asthma attack. *Thorax* 55: 19–24.

11 Department of Health (2007) *Making it Better: For Children and Young People*.

12 Royal College of Nursing and WellChild (2009) Better At Home campaign.

Access to a CCN service enables personalised packages of care to be established based on individual assessed needs and health and well-being outcomes,<sup>13</sup> allowing children and young people to be cared for in the setting of their choice.

### Rotherham complex health needs team

The complex health needs team is a nurse-led service providing support to children and young people with a long-term condition, or life-limiting or complex health need that fits in with the child's everyday life. The team consists of community children's nurses, respite nurses and carers, specialist nurses in diabetes, oncology and palliative care, generic children's healthcare assistants, special school nurses, an education nurse advisor, discharge facilitator and a children and family counsellor.

Five years ago services looked very different: staff groups were minimal, fractionalised, disparate and working in isolation. Children and families wanted support that fitted into their lives, they wanted children to be able to access school with the same ease as a well child, and they wanted support from confident nurses and carers. They also wanted services that followed the child "wherever they may be", and that could be accessed 24 hours a day. Many children were technology dependent and could not access short break provision through social care.

Currently, 658 children are being supported by the team. Feedback from children and families indicates that the "team-around-the-child approach" and the ability to follow the child wherever they may be have "significantly improved continuity and quality of care", "given assurance" and "enhanced coping".

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<sup>13</sup> Department of Health (2010) *National Framework for Children and Young People's Continuing Care*.

Costs of caring for a medically stable ventilator-dependent child in a paediatric intensive care unit (PICU) versus caring for them at home:

- the national average cost of caring for a child in a PICU is £2,067 per day or £754,455 per year; and
- the average cost of caring for the same child in the community is between £100,000 and £250,000 per year.<sup>14</sup>

Costs of caring for children requiring long-term ventilation:

- the cost of caring for a child on a PICU for 12 months in 2004 was £630,388;
- the cost of caring for a child on a high dependency unit for 12 months in 2004 was £301,888; or
- care could have been provided at home at a total cost of £161,174.<sup>15</sup>

The following table gives comparative costs for treating a child diagnosed with congenital central hypoventilation syndrome (CCHS), which involves long-term ventilation care. The costs cover a period of 12 months.<sup>16</sup>

Hospital costs (£ at 2002 prices)		Community costs (£ at 2002 prices)	
High-dependency long-term ventilation unit at £800 per 24 hours:	292,000	12-hour day care B grade home care worker £48,723 and team leader grade F nurse (0.2 WTE) £8,385:	57,108
Hospital services	647	Nursing and personal care	7,220
Community health services	5,412	Equipment	18,541
Social services	3,829	Hospital services	2,519
Education		Community health services	866
<b>Total</b>	<b>301,888</b>	Primary care services	2,007
		Pharmacy	8,132
		Disposable equipment and supplies	56
		Social services	7,142
		Education	
		<b>Total</b>	<b>103,591</b>

14 Murphy J (2008) Medically stable children in PICU: better at home. *Paediatric Nursing* 20(1): 14–16.

15 Noyes J (2004) *Evaluation of Health and Social Care Provision for Ventilator-dependent Children in the UK*. PhD thesis. University of York.

16 Noyes J and Lewis M (2005) *From Hospital to Home: Guidance on discharge management and community support for children using long-term ventilation*. Barking, Essex: Barnardo's.

## The Technology Dependent Children Project – Royal Brompton Hospital, London

The Technology Dependent Children project in London is reducing the time it takes to discharge children on long term ventilation (LTV) by providing a structured discharge pathway and outreach education and training packages. Presently, medically stable children on LTV are kept in high dependency beds for many months waiting for a complex package of home care to be in place before discharge. This is an inappropriate environment to meet a child's development needs – often siblings and other family members are not able to visit. It is also hugely expensive. The team at the Royal Brompton reviewed 68 LTV children who required a complex home care package and the cost of the hospital stay was £43million, based on an average bed day cost of £1500. At present, communication between acute and primary sector health care workers, social services, and commissioners is ad hoc and unstructured, leaving the central thread of the discharge process obscured. The team at Royal Brompton has identified that significant delays in discharge were due to a lack of urgency in decision making and lack of coordinated community care (including insufficient CCN services). This led to the development of an innovative web based decision support pathway (e-vent, winner of NHS London Innovator Award in Healthcare ICT) that can be accessed by hospital and community professionals, providing a single site for communication and a structured patient centred pathway. Information from e-vent can identify real-time delays in discharge and areas where lack of community resources is contributing to delays to discharge. Due to the extraordinary cost of these patients, savings, even for this small population, can be significant. Much of the knowledge gained here could be applied to other complex discharge processes resulting in better patient experience as well as significant savings to the NHS.

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### Safe governance arrangements/supervision of carers/support workers providing complex packages of care

Community children's nurses provide vital support, advice and supervision for the increasing numbers of non-registered staff who provide care. As more and more children are living with complex care needs, teams of non-registered staff are carrying out delegated nursing duties, caring for children who are highly technologically dependent, at home, in school and when accessing a range of community services. These staff spend long periods of time in families' homes where they may identify safeguarding concerns or find it difficult to draw the line between being an employee providing a service and being part of the family. Support, advice and supervision of these staff from skilled children's nurses can help providers to have the required governance arrangements in place.

### Training and ensuring ongoing competence of parents/carers/non-registered staff

There is an increasing need for skilled practitioners to train and assess children, young people, parents and carers, staff in educational and leisure environments and in the voluntary sector.

- To provide an increasing range and number of packages of care, local areas will have to train a large number of parents and carers.
- Many children and young people with long-term conditions need teaching about their condition, how to manage it and undertake a variety of nursing procedures. This is particularly important during adolescence where young people need to become increasingly independent.
- Good governance requires a structured system for ensuring all staff who provide individual care to children with nursing needs receive regular updates and assessment of practice.

Skilled children's nurses who are used to working in the community are required to provide this training and to develop a structured approach to ensure ongoing competency in those they train.

### Competency-based training for non-registered carers, NHS Coventry and NHS Warwickshire

Coventry and Warwickshire PCTs have developed a comprehensive training and assessment programme based on Steinaker and Bell's experiential taxonomy.<sup>17</sup> It is intended to train parents, foster carers, NHS and local authority staff, family link workers and voluntary sector workers to support children with complex needs.

Each competency has a document with a clear legal disclaimer to clarify the responsibilities of the trainer/trainee and their employer, PowerPoint teaching notes, handouts and workbooks with model answers. Both PCTs have increased training capacity by recruiting additional clinical educators in each of their CCN teams. Evaluation of the competency system demonstrates that it is now widely accepted and gives organisations the confidence to allow their staff to undertake the complex nursing care that some of the children need, increasing access to a wide choice of support packages and short breaks for children with complex needs.

<sup>17</sup> Steinaker N and Bell M (1979) *The Experiential Taxonomy: A New Approach to Teaching and Learning*. London: Academic Press.

What has been achieved?

- A set of clear standard clinical competencies.
- Safe and effective delegation of care to non-registered carers.
- Acceptance by families and trained staff that non-registered carers can safely care for children.
- Children and young people are now able to attend many different venues, making school trips and family holidays possible.
- Significant cost savings.
- Accurate costing of training.
- Inclusion in local university pre-registration training.
- Use in preceptorship of the newly qualified nurses.
- Wide national and international dissemination of the training tool.

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### Educator/trainer role, Warwickshire

In 2001 the NHS trusts in Warwickshire reviewed their children's continuing care service delivery. At that time Warwickshire had a small CCN team and a nursing agency provided the majority of children's packages of care. There were significant issues with this system, including high staff turnover, variation in skills, poor communication with other services and very high cost. A bid to expand the CCN team to include administration, a clinical educator role and a mix of nurses and support workers was successful. The cost saving was £902,840 per annum.

In 2006 the Diana team, which provides palliative end-of-life care, was also integrated into the team. Children with complex needs now get general community nursing support, packages of care and palliative care support from the team as required. This model has enabled integrated high-quality cost-effective services to be delivered in a sustainable manner.

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### **Co-ordination of a multi-agency package of care – acting as the lead professional**

For many ill and disabled children, the community children's nurse is the obvious person to undertake the lead professional role. Co-ordinating care is both vital for families who, in the absence of a professional undertaking the role, have the additional burden of having to do this themselves, and is a natural part of the CCN role.

In a report by CLIC Sargent<sup>18</sup> which makes recommendations to improve the long-term outcomes of young people with cancer, the importance of this role was highlighted, proposing the formal establishment of the role to include a practitioner who could demonstrate a wide range of skills, including:

- the provision of psychological and emotional support to children, young people and their parents;
- achieving an appropriate balance between acting as an advocate on behalf of the child/family and empowering the child and family to take control of their own situation;
- networking and co-ordination with other members of the multi-agency support team;
- knowledge of local resources and sources of support for children and families; and
- a high level of expertise within their own practice discipline and awareness of the skills, knowledge and expertise of other members of the multi-agency team.

### **Neonatal care (this has been included in this section but is relevant to all four groups of children)**

As a result of advancements in neonatal services, the outcomes for sick and very premature babies have improved; however, many of them will have a prolonged period of ill-health requiring nursing intervention. This frequently results in extended periods of hospitalisation, placing significant demands on parents who wish to be with their babies. Trying to maintain a "normal" life for other family members and sustain an income can put immense pressure on family dynamics.

Many of these babies could be safely cared for at home by their families with support from community-based nursing teams.

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18 CLIC Sargent (2009) *"More Than My Illness": Delivering quality care for children with cancer.*

### Neonatal outreach service, Cambridge University Hospitals NHS Foundation Trust

This service is managed by a lead nurse who has a team of experienced neonatal specialist nurses providing ongoing care within the home. The service is also supported by a neonatal discharge planning co-ordinator whose role is to provide discharge planning either into the home setting or back to their local hospital unit as part of the perinatal managed clinical network across the East of England.

At present a five days a week service is offered, but it is hoped to move to a seven-day service in the near future.

The advantages of the neonatal outreach team providing care in the home setting in partnership with the family include:

- a safe and effective way of discharging babies from hospital;
- continuity of care;
- up-to-date and evidence-based clinical expertise in a specialist area;
- social, economic and psychological benefits for families;
- savings in terms of cost and bed days in the acute setting;
- provision of training, education and support to parents and staff; and
- communication and liaison with other agencies and professionals in the community setting.

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#### 4d. Children with life-limiting and life-threatening illness, including those requiring palliative and end-of-life care

When a child who has a life-threatening condition reaches the terminal phase of their illness, the preference for both the child and family is to be able to die at home in familiar surroundings. However, a review found that 74% of children aged 19 and under suffering from conditions likely to have required palliative care (excluding neonates) died in hospital.<sup>19</sup>

**The contribution community children's nurses can make to the pathways of care for children and young people with life-limiting and life-threatening illness, including palliative and end-of-life care.**

<sup>19</sup> Craft A and Killen S (2007) *Palliative Care Services for Children and Young People in England: An Independent Review*. Department of Health.

To meet the needs of children and young people requiring palliative and end-of-life care both core community children's nurses and expertise in children's palliative care as part of a wider multidisciplinary team is required.<sup>20</sup> The same document stresses the need for this care to be available 24 hours a day, seven days a week. The ACT palliative care pathway sets out the CCN services required as part of comprehensive services.<sup>21</sup>

### **Diana team, Newham community health and care service**

The Diana team is a nurse-led multidisciplinary team established in 2006 and based at Richard House children's hospice. It works in partnership with the hospice to deliver community palliative care for 0–19-year-olds, including children with long-term ventilation needs. The focus is on respite, symptom control management and end-of-life care. This team also includes a clinical psychologist, play specialist co-ordinator and a team of healthcare support workers.

Newham has a population of 78,000 children and young people. The Diana service had 47 children and young people referred to the team during 2008/09. During 2009/10 there was a caseload of approximately 40, and 10 children received end-of-life care.

The local children's integrated commissioner invested in the expertise within the Diana service by increasing the workforce by 100% to enable the delivery of palliative care within the CCN service.

Key achievements have been:

- keeping children with complex healthcare needs, including the long-term ventilated children, out of hospital;
- planning and co-ordinating end-of-life care, ensuring that choice of place of death is offered;
- a considerable increase in productivity year on year, especially in the area of new referrals, as clinical professionals become more confident in the expert delivery of palliative care including end-of-life care; and
- establishment of a play service offering therapeutic play in the child's home. The benefits include improved self-esteem and body awareness (for example, in regard to enteral feeding and Hickman lines through playing with the dolls).

<sup>20</sup> Department of Health (2008) *Better Care: Better Lives. Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions.*

<sup>21</sup> ACT (2004) *The ACT Integrated Multi-agency Care Pathway for Children with Life-Threatening and Life-Limiting Conditions.*

For some children sensory play has helped with communication, stimulating development. In the play plans, the therapy is linked to the educational plans from school, enabling the child to explore in a fun context and learn new experiences.

Baby massage taught to parents has helped them to bond with their baby.

The clinical psychologist led a service user evaluation project, which was a formal, systematic and in-depth exploration of the experiences and views of families who access the service. It aimed to identify ways in which service users could become more involved in ongoing evaluation and development.

The Diana service also offers joint sessions with the siblings of the child who is approaching the end of life. Activity boxes for siblings have been developed. The psychologist works directly with siblings, helping them to cope with chronic illness in the family and the death of a sibling.

The quality of delivery of end-of-life care is captured in the words of families:

"Words cannot describe how much we miss our beautiful princess and hope with each passing day the ache in our hearts will ease. Thank you for being there when we needed help and reassurance."

"It was a pleasure to work with your team and if there wasn't a team like yours in the community, only God knows what P's life would have been like. You put smiles on my face despite the hard times I was going through and you made a comfortable life for P."

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Estimates show that for children with conditions requiring palliative care, the prevalence of complex needs is highest. Cost per family ranged from £2,600 for a CCN team that supported over 150 families to £8,900 for a team that supported 15 families (at 2007 prices).<sup>22</sup>

This clearly suggests that economies of scale exist, with lower costs overall for larger CCN teams.

<sup>22</sup> Lowson K, Lowson P and Duffy S (2007) *Independent Review of Palliative Care Services for Children and Young People: Economic Study*. University of York Health Economics Consortium.

# Annex. The experience of children, young people and their families

Children and young people who experience ill-health and disability are faced with significant variability of service provision, frequently leading to less positive outcomes and experiences. Some of these experiences are highlighted below across four pathways for:

- children with acute and short-term conditions;
- children with long-term conditions;
- children with disabilities and complex conditions, including those requiring continuing care and neonates; and
- children with life-limiting and life-threatening illness, including those requiring palliative and end-of-life care.

It is important to recognise that children may fall into more than one group at any one time or move from one group to another.

## Children with acute and short-term conditions

Children and young people are being admitted to hospital unnecessarily in some areas:

'The increasing high volume of children and young people needing emergency and urgent care, coupled with the significant variation in the length of stay, offers an opportunity for some organisations to provide better care more efficiently. By reducing the length of stay of patients who stay between 1 and 2 days (by an average of half a day) there are potential savings of at least £53 million (excluding length of stay of zero). The savings could be at least £161 million if the length of stay for patients staying more than two days is reduced by one day.'<sup>23</sup>

In a service redesign programme for the care of children presenting to accident and emergency departments where senior paediatricians triage children, one quarter of children who would have previously been admitted would be managed as outpatients or in the community, releasing savings of £129 million across the NHS.<sup>24</sup>

<sup>23</sup> NHS Institute for Innovation and Improvement (2008) *Delivering Quality and Value. Focus on: Children and young people emergency and urgent care pathway*, citing Dr Foster Intelligence using data from secondary user services using £228 excess bed day tariff.

<sup>24</sup> [www.evidence.nhs.uk/qualityandproductivity](http://www.evidence.nhs.uk/qualityandproductivity)

"In 2007/08, she had 14 hospital admissions lasting one to five days. Since the community children's nurse came in 2009, she has had only two. She has had a lot less acute admissions this year due to the nurses." (Parent)

'Acute illness in children with breathing difficulty, fever or diarrhoea and vomiting can be managed with nursing observation at home when hospital admission would normally be considered necessary.'<sup>25</sup>

## Children with long-term conditions

Children and young people who have long-term conditions have not experienced the same improvements in outcomes as adults with long-term conditions. For example, 84% of children under 16 with diabetes in England and Wales had poor or very poor diabetic control.

'The philosophy of home care benefits the newly diagnosed [diabetic] in limiting separation and allows the family to be in control from the outset, enabling them to absorb knowledge more easily in the home environment. Established patients have the confidence to contact the team with whom they have built up a relationship since diagnosis, leading to more home management at times of difficulty...In addition the rationale of care at home enables the whole family to be involved, and enables the nurses and dieticians to see how the family live and how diabetes care will be managed by their lifestyle.'<sup>26</sup>

Asthma UK estimates that 75% of hospital admissions for children with asthma are preventable. A disease management information toolkit for diabetes, asthma and epilepsy in children and young people is available at the Maternal Health Observatory (ChiMat) website at: <http://yhpho.york.ac.uk/IADDataServer/dmit/index.asp>

The toolkit enables PCTs to compare their emergency admission rates, bed days and lengths of stay with a range of different comparators. It provides comparative costings for community-based support and emergency admissions.

'The need for children with long-term conditions...to have access to high-quality specialist services, when needed, and appropriate care – including community nursing services – close to home, requires services to be delivered through effective networks of care.'<sup>27</sup>

<sup>25</sup> Sartain SA, Maxwell MJ, Todd PJ et al. (2002) Randomised controlled trial comparing an acute paediatric hospital at home scheme with conventional hospital care. *Archives of Disease in Childhood* 87: 371–375.

<sup>26</sup> McEvilly A and Kirk J (2005) Twenty years of a multidisciplinary paediatric diabetes home care unit. *Archives of Disease in Childhood* 90(4): 342–345.

<sup>27</sup> Department of Health/Department for Children, Schools and Families (2009) *Healthy Lives, Brighter Futures: The strategy for children and young people's health*.

Better management of long-term conditions such as diabetes, asthma and epilepsy during childhood will lead to increased life expectancy and greater opportunity for children and young people to fulfil their social and economic potential.<sup>28</sup>

"The community paediatrician who sees my child once a year at school does not communicate with the community children's nurse who does not see him regularly but responds to my cries for help. Neither communicate with my GP who I call when he [my child] is acutely ill. Why can't he have one care plan they all use?" (Parent)

CLIC Sargent found that frequent admission or long periods of time in hospital for children and young people with cancer can cause long-term harm through social isolation and interrupted education resulting in poorer educational outcomes and employment opportunities.

"Being sick is the easy bit. It is the other things – school, confidence, getting back to having friends, your emotions – that are really difficult. And yet children and young people are being left to cope with all this on their own." (Manvir Randhawa, cancer survivor, aged 19)

'Children with cancer want to lead ordinary lives, and being at home, or closer to home, gives them the opportunity to do exactly this. To enable children with cancer to spend more time at home, good quality community based clinical care should be available to all children regardless of where they live.'<sup>29</sup>

These findings are applicable to many children and young people with long-term conditions.

### **Children with disabilities and complex conditions including those requiring continuing care and neonates**

A survey conducted for the Better at Home campaign<sup>30</sup> found 186 children across England who had been in hospital for more than three months. One of the key barriers to discharge was the lack of staff to support parents and families, particularly community children's nurses.

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28 Ibid.

29 CLIC Sargent (2009) *"More Than My Illness": Delivering quality care for children with cancer.*

30 Royal College of Nursing and WellChild (2009) Better at Home campaign.

The following examples<sup>31</sup> demonstrate the impact on families when services are not there to support them in caring for their child.

There was a depth of emotional response in the workshop that reflected the difficulties, frustrations, bemusement and despair that parents could experience when community care was not working well and they felt marginalised or abandoned by a system that did not or could not care for their child. One mother explained how she had not had enough nursing care at home and that without this care children and families could not "live full lives without being pushed to their coping limits".

Another family described how difficult it was for people to really appreciate "living the life with a child with complex medical needs" particularly as "doctors don't get it".

In situations where parents did have a package of care in place, this did not always provide the continuing care and support they and their child needed. Some families and professionals described the situation of care and support "falling over" if trained carers were sick and could not cover a span of duty. When sickness cover could not be found, parents had to take over completely. This inevitably added to their physical and emotional stress. This lack of cover in the community meant that, for some families, there was no choice but for their child to be admitted onto the ward for overnight care. However, this breakdown in services could be further compounded "if the ward is busy or if it had D&V and therefore it's not appropriate for the child to be admitted, the child can't be admitted and has to stay at home".

"It shouldn't be considered reasonable/acceptable for a parent to be expected to do free slave labour 24/7 – not good enough to treat families this way."

As part of Aiming High for Disabled Children, £280 million was given to provide short breaks for disabled children with complex healthcare needs to help support their families.

"We often hear from families that are denied equipment costing £1,000, where their child then goes on to develop physical problems that often costs the NHS £10,000 plus to manage/treat. This mis-management creates an unnecessary financial burden on the government and distress and pain to the child."<sup>32</sup>

31 Taken from Carter B, Coad J, Goodenough I et al. (2009) *Community Children's Nursing in England: An appreciative review of CCNs*. Department of Health in collaboration with the University of Lancashire and the University of the West of England.

32 Newlife (2007) *It's Not Too Much To Ask: Campaign Report*, page 30.

## Children with life-limiting and life-threatening illness, including those requiring palliative and end-of-life care

The independent review into the care of children with palliative care needs<sup>33</sup> found that the provision of community children's nursing was critical to families' ability to care for their child at home, especially in the end-of-life phase, and yet 74% of children with life-limiting and life-threatening conditions die in hospital when they and their families have stated they would prefer to be at home.

"My life would be easier if there were nurses who could look after me at home rather than having to go into hospital."

"My life would be easier if I was able to go to school regularly and play with my friends as near to home as possible, with the help I need to help me join in the lessons and look after me while I am there."<sup>34</sup>

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33 Croft A and Killen S (2007) *Palliative Care Services for Children and Young People in England: An Independent Review*. Department of Health.

34 Department of Health (2008) *Better Care: Better Lives. Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions*.



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