“GETTING HOME”

An Evaluation of the impact, outcomes and added value step down care provided in a children’s hospice setting offers children, families, health and social care providers and commissioners.

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- Dr Jayne Price, Senior Lecturer, School of Nursing and Midwifery, Queens University Belfast (Co-Lead Researcher)
- Mrs Debbie Hewitt, Paediatric Discharge and Transitions Co-ordinator, Northern Health and Social Care Trust
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Foreword

No child should remain in hospital longer than is clinically necessary (DHSSPS, 2005)

For the past 13 years, Northern Ireland Children’s Hospice has been caring for children with conditions from which they are not expected to live into adulthood, and their families. The mainstay of this support is centred on providing skilled nursing and psycho-social care through our community and hospice based services. Over the years, we have extended our services in response to emerging needs and have developed effective partnerships with statutory health and social care services. We do this because we know we deliver the best for children and their families when we work together.

For decades, small numbers of children with the most complex healthcare needs have remained in hospital for long periods. While advances in drugs and medical management alongside technological developments have made home care possible, transfer to home often remains protracted. Northern Ireland Children’s Hospice staff participated in multi-agency discharge planning meetings for individual children and recognised a potential for our services to provide an alternative environment for care. Since 2010, two children and two young people (and their families) have availed of transitional step down care within Northern Ireland Children’s Hospice.

This study has provided the opportunity to evaluate the Northern Ireland Children’s Hospice step down service from the perspective of parents and professionals within the Hospice and the Health and Social Care Trusts. We were aware that other children’s hospices have provided similar care and have endeavoured to capture some of their experiences also.

Whilst findings from this study confirm the value of step down care within the Northern Ireland Children’s Hospice to parents and to service providers, this in itself, is not the solution to this complex problem. Addressing the needs of these children and their families requires a strategic, multi-agency response. The unique environment and specific skill set of Hospice staff places this children’s hospice in a position to make a meaningful, effective and cost efficient contribution to their care and to the quality of their lives.

No child should be in hospital longer than is clinically necessary. This is especially true for children whose lives may not be long. I commend this report to you.

Professor Dame Judith Hill
CEO
NI Hospice
Introduction

It has long been recognised that children who are ill are better cared for at home. Admission to hospital should be on the basis that this is the only environment where the care and treatment required can be provided, and should be for the shortest duration clinically possible. Providing the right care, in the right place at the right time and closer to home is a core principle within Northern Ireland strategy (Compton, 2011). Yet there is a small group of children for whom discharge is protracted, often stretching over many months or years. Typically, these are children with the most medically complex needs and multiple disabilities resulting from genetic or congenital impairments, severe infection or trauma. Often reliant on technology (including ventilatory support) these children require on-going care across the 24 hour period provided by highly skilled carers (including parents and professionals) within an environment that can respond to their needs (Hewitt-Taylor, 2007). As a consequence, such children often experience protracted stays in hospital, even when clinically well, whilst support plans are agreed between service providers and commissioners, funding secured, staff recruited, parents and staff trained and homes are, where necessary adapted (Hewitt-Taylor, 2011).

At a fundamental level, prolonged admission of clinically well children infringes a child’s rights (UN Convention on the rights of the Child, 1990). Article 23 states that children with disabilities should “enjoy a full and decent life in conditions that ensure dignity, promote self reliance and facilitate the child’s active participation in the community.” It goes on to say that these children have a right to special care, designed to ensure that the child receives healthcare services and recreation opportunities in a manner conducive to the child achieving the fullest possible integration and individual development. Whilst children need the skills and medical interventions available in hospital when they are acutely or critically ill, the hospital environment is not conducive to family life or to the physical, psychological or social development of the child.

Recent national and local reports continue to identify that children are experiencing prolonged periods in hospital when they neither had medical needs nor wanted to be there (Ludvigsen & Morrison, 2003). In 2009, 178 children hospitalised for more than 3 months were identified in 140 hospitals across England with care needs which could have been met at home (WellChild/RCN, 2009). In Northern Ireland, an inspection into services for disabled children in hospital acknowledged that no child should remain in hospital longer than clinically necessary (DHSSPS, 2005). This report gave cognisance to this growing group of technology dependent children and called for a regional approach to address their emerging needs. As many of these children have conditions which bring a high risk of death before adulthood, there is a pressing need to improve the process and the child and family’s experience so that the child, their siblings and parents have the best opportunity for family life.
Families and professionals supporting them are fully committed to the best place of care being, where possible at home, however the process of achieving this is complex (Price et al., 2011). What is being asked of these parents is immense; and whilst the complexity, and unrelenting nature of the care of these children is likely to daunt the most stable and resilient families, the impact is even greater on single parent families and those with less adequate family resources (Kohrman, 1991). For a small number of children, discharge home to their parent(s) is not an option, and the challenge then is to secure an alternative location of care for the child, through foster care, adoption or a residential facility.

Recently, the Northern Ireland Health and Social Care Board has led on the development of a regional discharge action plan to standardise the process of discharge for children to home, a local hospital or another suitable facility (HSC Board, 2013). While this plan will undoubtedly improve the process, in reality the hospital stay is likely to continue beyond the point where the child is medically stable. It is therefore worth considering if an alternative, transitional location of care would bring positive outcomes for children and families in terms of the child’s development and the child and family’s quality of life.

The need for transitional care has been identified nationally and internationally (NHS Confederation, 2009: Kohrman, 1991). However few such facilities exist across the UK. One service is provided by the Children’s Trust, Tadworth which augmented its core service for children with acquired brain injury, multiple disabilities and complex needs by developing a transitional care unit for technology dependent children in 2006.

Since 2011, Northern Ireland Children’s Hospice has provided transitional care for a small number of medically complex children, all of whom have been reliant on ventilatory support. The term ‘step down’ has been applied to this model, to reflect the transfer from a highly medicalised hospital environment with prompt access to a wide range of support services, to the more home-like hospice environment where care is delivered by a nurse led team which although highly skilled includes a greater percentage of non-registered staff. Discussions with staff in other children’s hospices also revealed some were providing a similar model of care. As yet there is no evidence to support the value of this model to children and families, service providers and commissioners. This study seeks to provide such information by scoping the experiences of children’s hospices across the UK, listening to parents and to professionals who have participated in step down care and gathering information on the costs of care across settings.
Research design and methods

Aim
The aim of this study was to evaluate the impact, outcome and added value step down care offered children, families, service providers and commissioners, when provided in a children’s hospice setting.

Objectives
The questions we sought to answer through our objectives were:
1. How many children’s hospices across the UK are providing step down care, and what can we learn from their experiences?
2. What are the views and experiences of parents whose children availed of step down care in the NI Children’s Hospice?
3. What are the views and experiences of professionals in NI Children’s Hospice and in statutory services that have engaged in the process of step down care?
4. What is the comparative cost of care across hospital and hospice settings?
The study consisted of four phases to address each of the questions posed.

Study time frame
Data collection and analysis took place between January and October 2013.

Ethical approval
Ethical approval was secured through the Office for Research Ethics Committees ((Northern Ireland) ref 12/NI/0186). The study was considered and approved by the research governance committees in NI Hospice and the HSC Trusts in which it took place. The principles of research governance were adhered to and participation took place on the basis of informed consent. Permission was obtained to record discussions. Information was anonymised and data held in accordance with the Data Protection Act (1998) and research governance requirements. A support strategy was in place should participation cause distress to the participants or members of the research team.

Phase 1: Scoping the current provision of ‘step down’ care provided by children’s hospices across the United Kingdom.

Participants
Children’s Hospices across the UK with in-patient facilities were identified through a Directory of Children’s Hospice Services held by Together for Short Lives.
Recruitment
The Directors of Care in the identified 44 Children’s Hospices were communicated with by letter. The letter outlined the nature of this study and requested the completion of a response form to indicate if they had no experience of step down care, if they were currently providing step down care or if they had provided it in the past. The following definitions were provided to guide their answer-

**Step down care**—a term used to reflect the transition from a highly medicalised hospital environment with prompt access to a multi-professional team of doctors, nurses and allied health professionals to the more home like hospice environment where care is delivered by a nurse led team in a closer manner to the way care will be delivered at home.

**Children/young people of interest in this study**—children who have experienced a prolonged admission to hospital and for whom the hospice is providing (or has provided) an alternative (step down) setting for care while care packages are finalised and family members/staff trained.

Responses were received from 24 children’s hospices, with 15 positive replies confirming they had experience of providing step down care.

Data collection
A questionnaire was forwarded to the 15 hospices to capture information on a range of areas relating to the hospice and its experience of step down care (see table 1). Hospices were requested to exclude children admitted for short periods (1-2 weeks) to recuperate from short admissions to hospital (e.g. post surgery) as well as children admitted to hospice for prolonged periods due to social reasons.

**Table 1: Areas of enquiry within the questionnaire**

<table>
<thead>
<tr>
<th>General information</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Scope of hospice service provided</td>
<td></td>
</tr>
<tr>
<td>• Age range of children/young people admitted</td>
<td></td>
</tr>
<tr>
<td>• Number of beds available and currently open</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Step down information</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Number of years providing step down care</td>
<td></td>
</tr>
<tr>
<td>• Number of children/young people who have availed of step down care</td>
<td></td>
</tr>
<tr>
<td>• Referral sources</td>
<td></td>
</tr>
<tr>
<td>• Inclusion of step down in service statement of purpose</td>
<td></td>
</tr>
<tr>
<td>• Step down service specification and admission criteria</td>
<td></td>
</tr>
<tr>
<td>• Provision of discrete step down beds</td>
<td></td>
</tr>
<tr>
<td>• Number of children that can be accommodated for step down care at any time</td>
<td></td>
</tr>
<tr>
<td>• Age profile and conditions</td>
<td></td>
</tr>
<tr>
<td>• Components of step down care</td>
<td></td>
</tr>
<tr>
<td>• Length of stay</td>
<td></td>
</tr>
<tr>
<td>• Funding</td>
<td></td>
</tr>
<tr>
<td>• General views</td>
<td></td>
</tr>
</tbody>
</table>
The questionnaire was piloted with staff working in a children’s hospice outside the UK to ensure its usability and ease of understanding prior to distribution. A reminder letter was sent after two weeks, with a final response rate of 53% (n=8). A questionnaire was also completed by Northern Ireland Children’s Hospice to facilitate comparison with the hospices participating in the study.

**Data analysis**
The questionnaires were analysed by a member of the research team and the data tabulated manually to identify trends and variations in the care provided. The free text sections seeking the views of hospice staff were analysed to identify recurring and disparate perspectives. The second researcher independently reviewed the data for accuracy.

**Phase 2: Exploration of the experiences and views of families who availed of step down care within NI Children’s Hospice in their transition from hospital to home.**

**Methods**
A qualitative approach was used to explore parents’ experiences.

**Participants**
Parents of children who experienced step down care in Northern Ireland Children’s Hospice (n=7) were invited to participate. Initial contact was made by phone by a hospice professional who gave a broad outline of the study and sought permission to forward further information by post. All families (n=4) expressed interest, however, the fourth child died before parents replied to the written request and hence fell into the exclusion criteria which eliminated parents who had been bereaved within the 6 months prior to participation.

**Data collection**
Data collection was via one-off, semi-structured, in-depth interviews to enable parents to tell their story. Since this study looked at family experiences of step down care it was decided that parents should be invited to take part together in parent pairs since a broader family view may be given as one parent may help filling in the gaps for the other. Circumstances dictated a sole interview for one parent (i.e. a single parent). All interviews were carried out by the same experienced qualitative interviewer and children’s palliative care nurse, who was independent from the children’s hospice. Interviews were carried out in the parent’s place of choice—normally their family home or in one case the children’s hospice. Interviews were recorded with parent permission.

**Data analysis**
The recorded tapes were transcribed verbatim by a professional typist who had signed a confidentiality agreement. Thematic analysis, a widely used method in qualitative research was used to understand parents’ experiences of step down care. This enabled a systematic approach to the identification of themes in data by means of a coding scheme (Braun & Clarke, 2006), treating accounts as a resource for finding out about individual knowledge or experiences. The 6 stage approach to thematic analysis (Braun & Clarke, 2006) was utilised (Table 2). Analysis was undertaken through an iterative process involving both researchers, whereby a proportion of the transcripts were independently analysed and the researchers came together to reach consensus and discuss the future direction of the analysis.
Table 2: Suggested stages of thematic analysis (Braun & Clarke, 2006)

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description of the process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Familiarising yourself with your data:</td>
<td>Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.</td>
</tr>
<tr>
<td>2. Generating initial codes:</td>
<td>Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.</td>
</tr>
<tr>
<td>3. Searching for themes:</td>
<td>Collating codes into potential themes, gathering all data relevant to each theme.</td>
</tr>
<tr>
<td>4. Reviewing themes:</td>
<td>Checking if the themes work in relation to the coded extracts (level 1) and the entire data set (level 2), generating a thematic map.</td>
</tr>
<tr>
<td>5. Defining and naming themes:</td>
<td>Ongoing analysis to refine the specifics of each theme and the overall story the analysis tells, generating clear definitions and names for each theme.</td>
</tr>
<tr>
<td>6. Producing the report:</td>
<td>The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.</td>
</tr>
</tbody>
</table>

Phase 3: Exploration of the insights and experiences of hospice and statutory health and social care staff who have engaged in the process of step down care.

Participants
Health and social care professionals across hospice and statutory services who had experience of working with families who had availed of step down care at the children's hospice were invited to participate. Four research sites were identified: the children's hospice, the regional children's hospital, and community services within a further two Health and Social Care Trusts.

Recruitment
Professionals (N=62) were contacted by letter by a principal investigator within each research site. The letter included an information leaflet outlining the aim of the study and requested recipients returned either an 'opt in' or 'opt out' form. The researcher undertaking the interviews then contacted those opting into the study to schedule the focus group. 26 professionals took part—their professional groupings are outlined in table 3.
Table 3: Professionals who took part in the focus groups

<table>
<thead>
<tr>
<th>Professional group</th>
<th>Number</th>
<th>Professional group</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurses</td>
<td>8</td>
<td>Carers (employed)</td>
<td>1</td>
</tr>
<tr>
<td>Doctors</td>
<td>1</td>
<td>Social Workers</td>
<td>2</td>
</tr>
<tr>
<td>Occupational therapists</td>
<td>3</td>
<td>Health care/senior healthcare assistants</td>
<td>2</td>
</tr>
<tr>
<td>Physiotherapists</td>
<td>1</td>
<td>Managers</td>
<td>5</td>
</tr>
<tr>
<td>Dietician</td>
<td>1</td>
<td>Educators</td>
<td>2</td>
</tr>
</tbody>
</table>

Data collection
Five focus groups were convened, with two groups taking place within one research site due to the large number of professionals consenting to participate. The groups were heterogeneous in nature to encourage a full exploration of different professional experiences of step down care (Goodman and Evans, 2010). They were formed on a site specific basis to maximise the benefit of bringing together participants with shared, similar characteristics (i.e. members of the same organisation) and experiences (Polit and Beck, 2008). In this case, participants had experience of step down care relating to the same child and family. Each group was moderated by the researcher who undertook the parent interviews and was independent from the hospice. The discussion was guided by a standardised written set of questions linked to this phase of the study’s objective and developed from the responses to the hospice questionnaire (phase 1). The groups were tape recorded with participant consent.

Data analysis
A similar approach was adopted to Phase 2 in that the focus group recordings were transcribed verbatim by the professional typist who transcribed the parent interviews. Thematic analysis (Braun and Clarke, 2006) was applied to the rich qualitative text of health and social care professionals’ experiences. In contrast to the interviews in Phase 2, the analysis importantly included identifying areas of both agreement and controversy reflecting how views are modified or developed through the group discussion (Goodman and Evans, 2010). Once more, an iterative approach to data analysis was applied by both researchers.

Phase 4: Exploration of costs of care across settings.

Time and resource constraints prohibited a systematic economic appraisal of costs. Instead, the costs of care for the last child who received step down care in NI Children’s Hospice were reviewed. (The costing strategy at this time was based upon the daily cost of care for this child). Fixed costs inclusive of staff salaries and overheads were accessed through the finance department. Variable costs were reviewed by estimating the percentage use of supplies by the child concerned as 1/7th total spend (hospice occupancy level-7 beds). Costs were also requested from the host Health and Social Care Trust responsible for ordering child specific consumables. In addition, bed night costs were requested from the regional children’s hospital. A review of the literature was undertaken to identify relevant costs for similar services.
Phase 1: The provision of step down care by children’s hospices across the UK.

General findings
Not surprisingly, all hospices reported they provided hospice care in line with the established model across the United Kingdom. This model is centered on the provision of holistic care for the child with a life limiting or life threatening condition and their family through life, death and bereavement. Core components of the services included planned and emergency short breaks, symptom management, end of life care, sibling support and bereavement and family support in hospice and community settings. Responses also reflected evolving developments in children's palliative care to meet the changing needs of this population. While five hospices accepted children/young people between the ages of 0 and 18/19 years (traditionally, the core age range for such services) three hospices offered young adult services up to 30 years and, at the other end of the spectrum, one response provided services only for babies and young children 0-5 years in recognition of a peak demand for palliative care in the neonatal and early years period. When asked the nature of their referral criteria, all hospices responded that they accepted children/young people with life limiting/life threatening diagnoses. Four hospices also responded that they accepted children with complex healthcare needs without a diagnosis of a life limiting/life threatening condition. The number of beds available and open in the hospices varied as outlined in table 4.

Table 4: Number of beds available and open in responding hospices

<table>
<thead>
<tr>
<th>Hospice</th>
<th>Number of beds in hospice</th>
<th>Number of beds open</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>2</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>3</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>4</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>5</td>
<td>14</td>
<td>12</td>
</tr>
<tr>
<td>6</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>8</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>NICH¹</td>
<td>10</td>
<td>6</td>
</tr>
</tbody>
</table>

¹NICH=Northern Ireland Children's Hospice
Step down care
On review of the data it became apparent that hospices apply the term step down care in different ways. For two hospices, step down care related to short term admissions (ranging between 1 day and 4 weeks), focused on recuperation post hospital discharge or supporting parents to care for their child when new procedures such as enteral feeding or assisted breathing were introduced. As the application of the term step down was in variance to the expected context for this study as interpreted by the remaining six hospices, their data was excluded from this section of the study.

Data relating to the number of years hospices have offered step down care and the number of children who have availed of this service is presented below.

Figure 1: Number of year’s step down care has been provided

Figure 2: Number of children who availed of step down care by year of admission to the hospice.
A total of 25 children across the seven hospices (including Northern Ireland Children’s Hospice) availed of step down care in the period of interest (Jan 2010-February/March 2013). 13 children were identified as requiring invasive ventilatory support. 17 of the children were recorded as having a neurological condition or neurological impairment. One response identified 2 children had received step down care for social reasons. While hospices were requested to exclude children who had experienced prolonged stays due to social circumstances, it was not possible to differentiate specific data relating to these children in the remaining questions posed, so they have been included in the analysis. There are few children recorded as receiving step down care in 2013. Two factors need considered-

1. Data collection took place in Feb/March 2013—therefore only covered the first 2/3 months of the year.
2. As the data is presented by year of admission, it is possible that step down care continued for children admitted in 2012 into 2013.

The underlying conditions of the children are recorded in Figure 3.

Figure 3: Numbers of children by condition recorded

- SMA type 1
- Duchenne muscular dystrophy
- Fast channel myasthenia syndrome
- Congenital myopathy (query)
- Central hypoventilation syndrome
- Post cardiac surgery
- Brain injury/trauma
- Neurological conditions requiring ventilation
- Neurological-complex seizures
- Otahara syndrome
- Jubert’s syndrome
- Symptom management
- Social reasons
- Diagnosis not recorded
Age profile of children and young people

The age profile of the children is displayed in the graph below (Figure 4). Data was missing on 3 children.

As anticipated, the peak age group of children requiring step down care is less than 1 year old. Of note though is the group of young people who have required such care in their teenage years. Cross referencing the data on diagnosis and age of admission indicates that for a small number of young people with conditions such as Duchenne Muscular Dystrophy or other neurological conditions, a critical event such as a respiratory/cardiac arrest in their late teen years resulted in emergency interventions including intubation and admission to intensive care. Weaning from ventilation subsequently proved difficult and led to their protracted admission in hospital and subsequent transfer for step down care. It is likely that some of these young people will require the support of adult rather than children’s community services. This is likely to bring additional challenges for young people and their families as they transition from children’s to adult care.

Length of stay

The time children were admitted for step down varied from hospice to hospice. The shortest duration was 2 weeks and the longest over 1 year. Average length of stay was reported by 3 hospices as 3 months. One hospice where children were admitted for step down care for short periods (2-6 weeks) stated that community care must be in place with a commencement date to ensure that step down care does not continue in the hospice longer than planned. The discharge planning process to hospice in this case was reported as protracted (> 6 months) as transfer would not take place until the community care packages were ready to support the child at home. Identified factors influencing the length of stay included the recruitment and retention of home care staff, delays in home adaptations, hospice bed availability and staffing levels and the abilities of the parents to take on the responsibilities of caring for their child.
Step down care processes
Hospices were asked if step down care was specifically referred to in their Statement of Purpose. This legislative statement is required by regulators of independent healthcare providers (including hospices) and outlines concisely the arrangements in place for the operation of the organisation including its philosophy of care and range of services provided. Two hospices responded that step down care was included in their Statement of Purpose. Another hospice acknowledged, that while step down has not been specifically covered in their Statement of Purpose, it has formed part of the hospice’s strategy over the past years enabling it to be provided when capacity allowed. One hospice stated it had a designated bed for step down care, although the response continued by stating the child would be admitted into a core service bed, leading the researcher to interpret that admission for step down would be prioritised over other types of admission when the need arose. In all other instances, children were admitted into a core service bed. One hospice only recounted that they did not participate in the discharge planning process prior to transfer to hospice. Five hospices stated they could provide step down care for one child at any time, with the sixth capable of caring for two children (albeit with additional challenges).

Hospices were asked to summarise the criteria they applied when considering a child for step down care.

Table 5: Summary of criteria applied by hospices when considering a child for step down care

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Responding hospices (n=6)</th>
<th>NICH criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meet hospice criteria</td>
<td>5</td>
<td>Meet hospice criteria</td>
</tr>
<tr>
<td>Hospice is best place for the child</td>
<td>1</td>
<td>Service capable of meeting child’s needs</td>
</tr>
<tr>
<td>Hospice can meet the child’s care needs</td>
<td>1</td>
<td>Funding agreed for hospice care</td>
</tr>
<tr>
<td>Funding has been secured</td>
<td>3</td>
<td>Care package agreed and progress underway to recruit staff</td>
</tr>
<tr>
<td>Staff and skill mix available are competent and have capacity to meet the child’s care needs</td>
<td>1</td>
<td>Future plan to discharge developed</td>
</tr>
<tr>
<td>Time frame to discharge/plans in place for return to home/clear exit strategy</td>
<td>6</td>
<td>Time frame to discharge identified</td>
</tr>
<tr>
<td>Responsibility/accountability for delivering training (hospice or statutory authority)</td>
<td>1</td>
<td>Clear lines of responsibility re training, provision of equipment etc</td>
</tr>
<tr>
<td>Statutory services aware that competency development is not undertaken by hospice staff</td>
<td>1</td>
<td>Identification of medical support model-designated paediatrician, access to specialist support if child becomes unwell.</td>
</tr>
<tr>
<td>Back up plan in place if child becomes unwell or hospice needs to close</td>
<td>2</td>
<td>Monitoring arrangements in place (including monthly meetings)</td>
</tr>
</tbody>
</table>

Hospices were also asked to identify the components of care offered as part of a step down service against a range of options.
Table 6: Components of step down care

<table>
<thead>
<tr>
<th>Components</th>
<th>Responding hospices (n=6)</th>
<th>NICH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Core Care</td>
<td>6</td>
<td>Yes</td>
</tr>
<tr>
<td>Training of parents in core competencies</td>
<td>5</td>
<td>Yes</td>
</tr>
<tr>
<td>Training of home care staff in core competencies</td>
<td>4</td>
<td>Yes</td>
</tr>
<tr>
<td>Facilitate home based care by hospice staff as part of transition process (option 1: 1-2 nights at home as part of discharge pathway)</td>
<td>1 (sometimes)</td>
<td>Yes</td>
</tr>
<tr>
<td>Facilitate home based care by hospice staff as part of transition process (option 2: hospice staff deliver care package at home upon initial discharge)</td>
<td>No</td>
<td>Yes (sometimes-)where geographical distances from the hospice permit)</td>
</tr>
<tr>
<td>Facilitate home based care by hospice staff as part of transition process (option 3: hospice staff are contracted to maintain package of care on ongoing basis)</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

One hospice commented on the partnership approach adopted with the community children's nursing team to the training of homecare staff. This mirrors the experience of Northern Ireland Children's Hospice where close partnership working to agreed training competencies enables both Trust and hospice staff to participate in the training of others who will contribute to the child's care.

**Funding**

Questions were posed on the sources of funding for step down care, whether step down was fully or part funded and if specific funding streams were accessed. Respondents reported that funding was secured through the local authority, most frequently through the Continuing Care funding stream (England). While four hospices sought full costs, three hospices reported they financially contributed to step down care. Costs were either on the basis of a set rate, calculated on an individual child bases (5 hospices) or in accordance with a scale that took account of the level of care needs, adjusted for the specific circumstances of each child (2 hospices-within the same organisation).
Table 7: Cost of care

<table>
<thead>
<tr>
<th>Hospice</th>
<th>Cost per night (most recent case)</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Set cost £750.00 per night</td>
<td>No additional comments</td>
</tr>
<tr>
<td>2</td>
<td>Set cost £850.00 per night</td>
<td>Currently working on costs for different packages at time of completing questionnaire</td>
</tr>
<tr>
<td>3 and 4</td>
<td>Scale</td>
<td>Scope to negotiate costs on individual needs</td>
</tr>
<tr>
<td></td>
<td>1 staff member : 2 children £750</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 staff member per child £1500</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 staff members per child £2000</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Individual child basis £580</td>
<td>Based on hourly costs of staff required to care for child inclusive of extra duty payments. Hourly costs of care packages approved by Board.</td>
</tr>
<tr>
<td>6</td>
<td>£681.89</td>
<td>Based on hourly costs of staff, management charge and overhead percentage.</td>
</tr>
<tr>
<td>NICH</td>
<td>£750.00</td>
<td>Staff hourly costs, management, ancillary and administration %, consumables and overheads.</td>
</tr>
</tbody>
</table>

General views
Free text space was provided for hospices to record their general views on step down provision, focusing on what worked well, the challenges experienced and its perceived value to the child, family and statutory services.

All hospices identified step down care as a valuable and positive service. Benefits for the child and family related to the opportunities for families to be together and to avail of the wider range of hospice support. Parents had the time to consolidate competencies in their child’s care and to gain confidence through a gradual transition from hospital to home. For statutory services, freeing a hospital bed for acute admissions was considered an advantage of step down care.

For the hospices, gaining and maintaining staff competencies was considered a challenge as well as an opportunity. One hospice was challenged to identify an effective and efficient process for staff to gain specific competencies not currently held by the team. These challenges related to securing an appropriate environment where nurses could gain supervised practice and the hours required to develop practice to a competent level. In contrast, for those teams possessing higher level care competencies, the presence of children for step down care were considered an excellent opportunity to maintain the team’s skills. Access to allied health professionals was also an issue for one hospice who did not have a physiotherapist, occupational therapist or speech and language therapist on their team. This was particularly difficult when the child resided outside the borough where the hospice was located.
Improved partnerships between hospital and statutory services were seen as a positive outcome. Through step down, strong links were developed with community nursing teams to the point where co-ordinated training took place across both services. Links were also improved with local hospitals. Central to the process were effective lines of communication, early discharge planning with full engagement of relevant parties, clear roles and accountability and agreement on funding responsibilities.

Wider challenges reflected the reality that step down is, for the hospices concerned a new service provided in an ad hoc manner in the main when circumstances permit. The variability in demand makes it difficult for hospices to commit to investing resources and managing staff rota. When children are admitted into core service beds it is then either not possible to commit to step down care as demand for short breaks is prioritised, or else the short break service is compromised for other families reliant on this aspect of hospice care. A different model of care is therefore required, with one respondent commenting that step down needed to be a stand-alone, fully funded service (potentially by the hospital or local authority).

**Comparison of Northern Ireland Children’s Hospice experiences with the six responses.**

In general, responses received were reflective of the experiences of Northern Ireland Children’s Hospice in its provision of step down care for four invasively ventilated children/young people with underlying neurological conditions. Although this service covers all of Northern Ireland, these children/young people resided in Trusts located closest to the hospice. Two situations involved the care of young people aged 18+ and required negotiation with adult community services, bringing an added dimension and challenge not recounted in the questionnaires received. In our experience, adult nursing services, for example were less familiar with care processes such as enteral feeding and ventilatory support. This required them to assess risks they had previously not encountered and to develop new contingency strategies to enable them to participate in the young person’s care at home.

Children/young people tended to participate in step down care for a longer duration in Northern Ireland Children’s Hospice compared to elsewhere. Transfer from hospital, once it was agreed that the child’s condition was stable and the hospice was well placed to meet their care needs tended to happen swiftly (within 1-2 weeks) on the basis that a preliminary plan was in place for the projected discharge to home (The children, had by this time been in hospital for many months to years.) While one young person was transferred to home after four months, for others step down extended to over 9 months. A significant contributory factor in some cases was the extreme impact the child’s care needs had on family life and the family’s capacity to develop the competencies required to care for their child within a wider parenting context rather than focusing solely on the completion of individual tasks. Protracted admissions also had, at times, a detrimental impact on core Northern Ireland Children’s Hospice services by restricting the availability of respite provision for other families. Where possible, this was counterbalanced by ‘opening’ an additional bed.
Phase 2: Exploration of the experiences and views of families who had availed of step down care within NI Children’s Hospice in their transition from hospital to home.

The narratives recounted by the parents were all individualised and the children reached different stages in terms of the ultimate goal of ‘being at home’, yet commonalities were present as highlighted in the thematic analysis carried out.

These narratives centred around 4 main distinct but interconnected themes - ‘Away from home’ ‘Wanting home’, ‘Feels like home’ and ‘Being at home’. Each theme was made up of a number of subthemes (see Table 8).

Table 8: Parent themes and subthemes

<table>
<thead>
<tr>
<th>Theme name</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Away from home</td>
<td>Need for hospital care</td>
</tr>
<tr>
<td></td>
<td>Existing not Living</td>
</tr>
<tr>
<td></td>
<td>Fragmentation of family life</td>
</tr>
<tr>
<td>Wanting home</td>
<td>Desire for normality</td>
</tr>
<tr>
<td></td>
<td>Facing multiple obstacles</td>
</tr>
<tr>
<td></td>
<td>Another option</td>
</tr>
<tr>
<td>Feels like home</td>
<td>Child and family as the focus of care</td>
</tr>
<tr>
<td></td>
<td>Learning to parent differently</td>
</tr>
<tr>
<td></td>
<td>Little things are big things</td>
</tr>
<tr>
<td></td>
<td>Living not existing</td>
</tr>
<tr>
<td></td>
<td>A short term fix</td>
</tr>
<tr>
<td>Being at home</td>
<td>Precious time, Precious memories</td>
</tr>
<tr>
<td></td>
<td>Overcoming the obstacles</td>
</tr>
<tr>
<td></td>
<td>Almost invisible but there</td>
</tr>
</tbody>
</table>

Theme 1: ‘Away from home’
Parents started their stories by recounting a time when it became apparent (usually suddenly) that their child needed medical care and intervention in hospital. The sudden realisation of the necessity to be ‘away from home’ happened either after birth when the baby had serious health care needs or following a major health event, for example a respiratory arrest.

‘He had Duchenne muscular dystrophy, which was life-limiting, so it was, so he…as his life went on, his life was shorter, but one day, he just cardiac arrested [clicking fingers].’ (2D)

‘He’d had a bit of a chest infection the day before, and the GP had given us antibiotics and, eh, he just seemed to go downhill within one or two hours. So I phoned Contactors Bureau, and they said they could hear him breathing on the phone and it wasn’t good, and they sent an ambulance.’ (3D)
The 3 subthemes - the ‘Need for hospital care’, ‘Fragmentation of family life’ and ‘Existing not living’ charted parents’ changing thoughts, feelings and anxieties during that time.

Initially parents saw the merit of their child being in hospital as they viewed it, at that stage as a place for ‘getting fixed’ or ‘made better’. However, after an initial period, hospital seemed to become the focus of many worries and concerns. Family life became fragmented.

‘The way we were working was...because the kids still had to go to school and...life still had to kind of go on, so, em, I would have went down first thing in the morning. Yeah, I would have got the kids out to school, drove down first thing in the morning, and ((dad's name)) had stayed all night with [child's name].’ (2M)

At a certain point parents seemed to realise that there was no medical improvement in their child’s condition. Indeed families then viewed hospital as a place that was not suitable and where the child’s safety was compromised (where they perceived care as less than the standard they expected for their child and where their child was at risk of infection/immediate death). They were also frustrated at the lack of stimulation for their child.

‘He was just sort of sitting on the bed, you know, playing with his toys, doing whatever he was doing, but...there was no stimulation at all. The furthest he was was out at the door.’ (1M)

D: He was in the wrong place.
M: He was a young...a young boy with special needs. He was like a 10 year old, you know...?’ (3M&D)

‘You could physically see ((child's name)) was giving up. There was nothing... I mean, he was existing not living.’ (2M)

The combination of these thoughts, experiences and anxieties seemed to drive parents’ desire of ‘Wanting home’.

**Theme 2: Wanting home**

‘Wanting home’ commenced for parents with the realisation that parents did not want hospitalisation to continue especially if it seemed their child was going to die there. The impetus for ‘wanting home’ normally arose from the perception on the part of parents that there was nothing significant being done for the child from a medical view point and home would be the best place for the child to be. The desire for home seemed borne out of the need for some semblance of normality (subtheme 1) for the child and family and the potential for clinical or emotional harm to the child in the hospital as evidenced below.

M: We kind of passed each other, the kids all passed each other...you know, it was...it was a...
D: It broke up family life like, I mean... (2 M and D)

‘So I – I kind of went a bit mad and said...everybody in this ward will get better. If he gets an infection, he’s going to die!’ (2M)
‘[Child’s name] was up in [name of hospital ward] and he moved into this wee side room, which was white walls and white ceiling, and he was just lying there looking at them, and he was going downhill even looking just in the room. We think it was the environment, the environment.’ (2M)

Despite the drive to be at home, parents recalled being anxious about how they would manage the child’s complex technological needs and a number of obstacles both internal and external to the family were seen as hampering discharge home (subtheme 2: ‘Facing multiple obstacles’). Achieving the skills and confidence to parent their child was seen as a challenge as was the protracted and laborious process of securing the necessary funding and community resources to enable discharge to home.

‘And then they sort of thought, look… Well, between them and between me, I couldn’t do this care. There’s just far, far too much.’ (1M)

‘So, we did meet with her boss and we tried to put it quite strongly that, eh, we need this package in order to get him home. Whilst she didn’t say, no, well, we can’t provide it, these… these… this rationale was presented of “I don’t have people trained” and it’s hard to get a number of people to give you 24-hour care and this will take a long time…’ (3D)

‘And he mentioned, he said, “I hate to mention money, but we cannot financially keep on…” And at that stage, I said, “Well, can we take him home? Can we get a ventilator and take him home and I’ll look after him?” and he said…and I knew…it was impossible at that stage, but it was anything rather than let him go back to the ward.’ (3M).

Through the ensuing struggles and battles that parents waged, ‘Another option’ (subtheme 3) became apparent—the service provided by Children’s Hospice.

‘Well, I sort of…I asked…then I asked, do you know, what sort of…you know, place was it, and what did it involve. And then that’s when they had said that’s…you know, what all was here, there was more for him to do.’ (1M)

Some parents initially dismissed the idea of hospice due to the misconception of what the hospice was like, but after a visit the option quickly became the route out of hospital that parents so desired.

‘Yeah, the children’s hospice, and they brought us up to view the – because when we heard “hospice”, we thought right away, no, he’s not going to hospice. I thought hospice was a dreary place just for people who are dying, you know what I mean, and…we were set, or I personally was set firmly against it, but they came and they brought us up and as soon as…we set foot in the place, we just knew it was the right place.’ (2D)

Although hospice was not home, the benefits became quickly apparent as for the children and families it was somewhere that ‘Feels like home.’
**Theme 3: Feels Like Home**

‘Feels like home’ captured parents’ multiple positive experiences of Northern Ireland Children’s Hospice, in that the hospice environment mimicked the home environment with the additional reassurance of highly skilled responsive clinical care. Such a secure and relaxed environment, where the child and whole family felt safe and cared for contributes to the ‘feels like home’ theme. This was contrasted with that in hospital.

‘Yeah, we felt really secure, really, really secure.’ (2M)

‘It is definitely far homelier. You know, you’re sitting drinking coffee with the girls and… everybody gets on, do you know? You have to go and get your coffee round at the canteen or… They’re too busy in the hospital…. they’ve more time in hospice.’ (1M)

The theme gave rise to 5 subthemes. The first sub-theme—‘Child and family as the focus of care’ linked to the capacity for the family to be together and added to the sense of homeliness.

M: And then, [sister’s name] at that time, [sister’s name]’s seven now, but she was only four, and em, she had said, “Can I hug him?” and they lifted her and put her in the bed beside him, put her in the bed beside him.
D: And she curled up beside him and they watched TV.
M: And he just kind of… [child’s name] just…smiled, you know.
D: Picked…his eyes lit up again.
M: Because that’s… that’s the way it was at home, you know, and… (2M and D)

‘And we were given two bedrooms, a bedroom for [dad’s name] and myself, and a bedroom for our three other children, and we lived like that for three months.’ (3M)

All the child and family needs were identified and addressed. In sometimes quite simple ways it often was ‘Little things that were big things’ (subtheme 2)- the attention to detail that was often overlooked in the hospital.

M: The next day was like a new child. You would never … In one day. I had never seen – I had never seen nothing like it in my life. I think it was more immediate. I think when they took [child’s name] out of the ambulance bed – it was white sheets, white, you know, very clinical, and they put him in a bed with dinosaurs all over the duvet covers, and there was colour…
D: Duvet, and colourful room… paintings on the wall, toys…
M: And… everything was… soft furnishings and very bright lights and… very colourful, and I think he just… he was automatically stimulated, you know. (2M and D)

D: The very first thing they did was to take him, oxygen, IV, four of them, they wheeled him, in his bed, down to the bathroom, and they bathed him, they washed his hair, they put on his own PJs. I brought in all his wee things from home – his cushions to rest his arms and his feet and all of that, and the very next day, he wakened up.
M: The turnaround was incredible. Just the fact that he was getting care that was appropriate and being comforted and supported…made the… complete difference. Absolutely, in the appropriate environment. (3M and D)
Parents recognised that by hospice taking care of daily tasks like preparing meals, precious, family time was freed up which in turn enabled them in ‘Learning to parent differently’ (subtheme 3). This was associated with developing the knowledge, skill and confidence to parent their child with their different and complex care needs.
In direct contrast to the child and family experience in hospital, hospice was seen as creating that homely family environment where ‘Living not existing’ (subtheme 4) happened.

‘It is a brilliant place now for kids to be, and just how much [child’s name] has come on has made me feel that it is a good place for somebody to come from a hospital to, you know, to the hospice to be stepped-down, to go home, you know.’ (1M)

Whilst ‘feels like home’ prevailed in the stories of parents, there came a point where parents realised that hospice was not for the long term but was providing a ‘Short term fix’ (subtheme 5). The need for ‘Being at home’ arose again.

M: Yeah. I mean, the Hospice…was always – I will always be deeply grateful to the Hospice, but because we were spending a long time there, there was a point that I got very depressed…
D: Aye.
M: And em, I needed…some counselling and I needed some help. As good as the Hospice was, it wasn’t family life. This isn’t how…you’re meant to live as a family.
D: No. We never had a family in three months, you know what I mean…
M: You know, em…and I found it very difficult, and em…I had spoke to [name of hospice nurse] and said…as much as it’s good and…I don’t want to seem ungrateful, I want to be home – he’s my son and I want him home. (2M and D)

Theme 4: Being at home
‘Being at home’ seemed to be the ultimate goal for children receiving step down care and their families; and their narratives reflected its importance for both parents and also for staff (as parents saw it). For each child/young person though, their journey ended in a different way. ‘Being at home’ (i.e. completed transition from hospice to home) happened for one family, for another family, they equated being at home with short day visits. One parents’ story was still ongoing at the time of the interview and the child remained at hospice while issues relating to being at home were worked through.

Sub themes of ‘Overcoming the obstacles’ and ‘Often invisible but there’ arose out of this theme.

Parents indicated an overwhelming view that whilst hospice provided such a welcoming, relaxed and homely environment, they continued to experience frustration as they tried to overcome the obstacles blocking their path to their ultimate goal of being at home. Each parent recognised the internal personal/family obstacles they had to overcome in terms of learning to care and having new confidence to care, but obstacles beyond their direct control linked to securing packages of care continued to cause untoward stress. Parents often perceived these obstacles as hampering, or diluting in some way their precious time of ‘being at home’.

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1Discharge to home was achieved for 2 of the 4 children who received step down care.
2In this case, the young person’s condition deteriorated and discharge to home was no longer the goal.
M. But the thing with the…with the Trust and stuff was, we felt that was what slowed it down.
D: ‘Nothing to do with the Hospice, the Hospice had everything set in place. They were happy, we were happy. The Trust and all the ins and outs round it slowed it all down to get…
M: To get the package…to get the package here. (2M & D)

Even when the child got home there were still obstacles to overcome, e.g. getting into a routine or obtaining supplies.

‘But even when we got him home, there was problems, like see with supplies and all, the things you needed, and the Trust…they were actually trying to set everything up, and sometimes supplies never arrived. So, we’d go back to hospice nurse, and we just lifted the phone and said, [hospice nurse’s name], look, we need such-and-such, and she would have phoned round the people that - we don’t know who to contact.’ (2D)

The reality of being at home and the responsibilities that brought for the family proved initially daunting, but this transition was eased by the presence of hospice staff who continued to provide support in a professional and expert way. Parents commented that the staff knew when to be present and when to step back-equating this with being ‘almost invisible, but there’. They continued to build confidence but artfully knew when to retreat, giving parents their rightful place at the centre of their child’s life and care, thereby facilitating family life.

M: We got him home for half a day with the physio and nurse…that took such organisation.
D: They got in an oxygen machine, oxygen cylinders…
M: Suction catheters…They came out and made sure that his room was okay and we were able to get granny and granddad up, and his aunt and uncle, and we took him outside onto the decking and we had a party almost. Our daughter did the cooking and…And then, em, we got him home again and they left us for a few hours. (3M and D)

Whilst hospice staff were always there and available at the end of the phone, a shift in the relationship was experienced when the step down process was completed and the child was at home full time. Severing of the intensive, reciprocal relationship developed between hospice staff and the child was a wrench for all concerned.

‘Aye. See when it came for the [name of the Trust] to take over in January the [hospice] girls were devastated like they had to leave and they wanted to look after him. That was a big-not only on [our son] or me or her, but on the rest of the…the two girls and the two boys, because they became so close…’

Irrespective of the final outcome of the step down process, families recognised the gift of family time the experience had brought them. Such ‘Precious time’ (subtheme 3) in turn generated some very precious memories after the child/young person’s death-something parents considered would have been impossible within the hospital setting.
‘I thought, how, how…? And I said to [dad’s name], “We are never ever, ever going to be able to thank them, no matter how much fundraising we do or whatever. We can never, ever thank them for what they’ve given. They’ve given us three months of quality time with [young person’s name] that we wouldn’t have had.’ (3M)

D: It’s because of the Hospice we got all them months home in a normal environment with [child’s name].
M: Yeah. We’re both in no doubt that if [child’s name] didn’t move to the hospice, he just would have died in…
D: He would have died that August (2M and D)

M: But everything within the Hospice…
D: Was positive.
M: Was definitely all memory-making.
D: The fun and the laughter…
M: We took about 2,000 photographs. (2M and D)

Phase 3: Exploration of the insights and experiences of hospice and statutory health and social care staff who have engaged in the process of step down care

Analysis in and across focus groups gave rise to 5 common themes and associated subthemes which help explain the experiences of professionals caring for children and families who availed of step down care at the children’s hospice (as outlined in Table 9). Professionals across Trusts and professionals groupings were in agreement about the complex challenges inherent in ensuring these children and their families were ready for discharge home.

Table 9: Themes and subthemes emerging from the professional focus groups

<table>
<thead>
<tr>
<th>Theme name</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Long road home</td>
<td>A battle every time</td>
</tr>
<tr>
<td></td>
<td>Combating impatience</td>
</tr>
<tr>
<td></td>
<td>Addressing the risk</td>
</tr>
<tr>
<td>Living again</td>
<td>Promoting normality</td>
</tr>
<tr>
<td></td>
<td>Flexibility in caring</td>
</tr>
<tr>
<td></td>
<td>Expert support</td>
</tr>
<tr>
<td>Learning to care</td>
<td>Teaching parents to parent again</td>
</tr>
<tr>
<td></td>
<td>Supportive environment</td>
</tr>
<tr>
<td></td>
<td>Professional Competence building</td>
</tr>
<tr>
<td>Developing Professional</td>
<td>Trust and transparency</td>
</tr>
<tr>
<td>partnerships</td>
<td>Organisations working in tandem</td>
</tr>
<tr>
<td>Best place, best care</td>
<td>Benefits of the service</td>
</tr>
<tr>
<td></td>
<td>Restrictions of present service</td>
</tr>
<tr>
<td></td>
<td>The future service</td>
</tr>
</tbody>
</table>
**Theme 1: The long road home**

Professionals across groupings identified the long protracted journey home for these children and their families. Staff clearly recognised and agreed that the hospital was not the best place for these children and limitations in the experience for children 'stepped down' from the regional centre to their local hospital were also raised in terms of their health, wellbeing and development. The complex process to get the child home resulted, in part from the need to assess and address the multiple risks involved, to secure funding, to employ and train carers, to train parents and possibly make adaptations to the family home. These factors coupled with the complexity of the child's needs, resulted in a time consuming process which frustrated staff trying to work together to meet the individual needs of the child and the family.

‘Em, funding agreed, carers recruited, trained, then parents, train family well enough to get home, and as much as we try to make that short, invariably, it's a long process, em, depending on the complexity of the child and the resources available in their area’ (FG2)

The resources available in the area where the child lived also had an impact on the ‘road home’ and staff in the hospital and community settings perceived this as ‘a Battle every time’.

‘It feels like a battle every time you’re trying to…send a child home, it’s, oh, here we go…’ (FG2)

Where hospital staff wanted children discharged home in the interests of the child and family, they were also acutely aware that the child's protracted admission prevented the bed being used by other children. There seemed at times a disconnect regarding the different pressures underpinning the determination on the part of professionals to get the child home.

‘We’re under increasing pressure from the hospital side about blocking beds, needing to move, winter’s coming in, infections are rife, and it’s move, move, move. So, we’re being propelled and driven along a road at a rate that…the two things are at odds necessarily with each other.’ (FG3)

‘I suppose my issues are that…once the hospital decide they want the child out, that’s the child’s going out, and their interest nearly is just like, you know, “We need this bed”’ (FG4)

Inherent in the ensuing battle and the long road home was the overwhelming need to manage risk.

‘It can be protracted, but it’s protracted for a reason: because of the risk management or whatever. It’s just not for kind of the hell of it.’ (FG3)

Risks were multi-layered and centred round the child's complex technology needs. Social needs were also often prevalent and a major issue for professionals.

‘Well, just from a nursing perspective, the children we’re talking about are the most, em, from a risk perspective, most…at most clinical risk, so there are significant risks that, from a nursing perspective, you need to consider and try to manage as best can, given that you’re going into a home and you’re coming out of the hospital setting, and I suppose that’s where I work closely with social workers. Alongside the clinical risks, there’s almost always significant social risks as well.’ (FG3)
At times ‘Addressing the risk’ seemed insurmountable, with pressure mounting on all sides while staff were aware that the child and family were caught in the middle in a less than optimum situation.

‘Yeah, so prolonged….and it’s the families, poor families who are tripping up and down here, with other siblings at home, and it’s just, you know… No matter what we try [laughs], from this end, no matter what we try and put in place or we suggest or…it’s the same…there’s no shortening – the timeframe hasn’t got any shorter, sure it hasn’t?’ (FG2)

Thus the hospice became an option for the most complex children within the journey through ‘the long road home’. Yet barriers were also evident with some parents initially reluctant to go to hospice as they viewed it as being synonymous with death.

These perceptions were allayed one they had the opportunity to visit.

‘And their perception of hospice was “No way, absolutely not, no way!” but once they got in through the front door, it was a completely different story.’ (FG1)

Skilled community staff talked about the need to broach the topic of hospice gently and in a gradual approach.

‘And gradually we’ll mention it, and then we’ll not talk about it, and then we’ll mention it again and build it up. And if these people are long-term in-patients, you know, they probably will have met families who have gone through the hospice, and they’ll say, “No, no, it’s not what you think at all – it’s very good.”’ (FG4)

What was made clear from discussions within groups was that transfer to home following step down in the hospice did not mean the journey was over- many battles still were experienced. Families felt safe and supported in hospice, having built trusting relationships with hospice staff and the transition to home led to a loss of such relationships which guided and supported them through the step down process. This necessitated forming new relationships with a different set of professionals.

‘Yeah. I mean, they found it so hard to come here, and it took them so long to get to know us, and then they got to know us and then it was a transition to home and then they had to get to know new staff, and then it was the same all over again. And then, by the end of it… you know, they [Trust staff] were the golden girls in the end.’ (FG1)

In addition was the recognition that the risk was potentially continuing for families, requiring close and intense support. The ‘long road home’ never really ended.

‘Discharging these youngsters, whether they go from hospital to home, or from hospital to home via step-down arrangement, is only the beginning. You know, our experience has been that if we can get around the safeguarding issues, which, for me, are the ones that have cropped up, and even we get them home, you’re constantly walking a tightrope, and the problem is, if home doesn’t work out, where do we go with them? Where do you place them? And, inevitably, you can’t, and inevitably you go back to the hospice and you say, “I know we went in one door and out the other, but we’re…”’ (FG3)

Theme 2: Living again
Notwithstanding potential long term issues for children and families, staff in both hospital and community teams saw hospice as a perfect option for many of the most complex children. Both children and families benefited from time in hospice regardless of whether they got home full time or not.

‘Regardless of the outcome, and two went home, and two didn’t, but in a sense, that didn’t really matter because it was what happened in that period of time…all the judgements that the care team make in terms of opportunities, seizing the moment, doing this, doing that, doing that risk assessment as you go along, saying we can do this safely – it’ll be fine. All of that…justifies because what…what we’re setting out to do is to provide a transition back home, or as close to that as we can, and I think in…if you look at the quality of life for all four, that was achieved, regardless of the outcome. And I guess that’s what we do all the time, because you don’t focus on the outcome, you focus on the now,…’ (FG1)

This theme captured the overwhelming belief on the part of professionals that when children and families were being stepped down into hospice they were ‘Living again’ in the full sense of the word and being enabled to do so. Their living was curtailed within the hospital environment, where they became institutionalised and where their medical needs were the main priority, and where it was not possible to the address the child’s other needs the same extent.

‘One of the other families as well, what they would have said was that, up until their child came here [hospice], they were waiting for him to die in the hospital, what they were doing on a day and daily basis. Here, they learned to…you know, to enjoy him living again. It was the way that they…what they would have talked about, and they were able to enjoy those experiences and able to just allow themselves to enjoy the days that he then had, whereas, in the hospital, they were just waiting for him to go really.’ (FG1)

Central to this ‘Living again’ theme, was the importance of promoting normality, something that was unachievable (as staff saw it) within the hospital environment. Consensus existed across groups and professionals regarding the fact that in ‘Promoting normality’ hospice was able to address all the needs of the child in a relaxed and homely environment, something that the hospital environment could not provide.

‘So…and then they get here (hospice) and the care that we provide meets a whole lot of needs that weren’t being met, em, not through…just because it was a different setting.’ (FG1)

Such was the conviction of professionals regarding the hospice’s capacity for ‘Living again’, was the strong and serious belief that the hospital environment by contrast was not only doing a disservice but was harming children and putting them at risk.

‘But it’s something…that we’re missing out in these children’s needs in hospital because, actually, are we damaging them keeping them in that environment for such a prolonged period of time when they’re not unwell?’ (FG4)
‘When you talk to staff on the wards, because I think they share the views that we all do, just the impact on the child and the family, that it’s not the right experience, and these children are being constantly exposed to risk of other infections, and that’s…that isn’t right, by any standard.’ (FG2)

Promoting normality within hospice included addressing a child’s physical, emotional and developmental needs. The fact that hospice could provide stimulation, enabling the child’s development to flourish was evidenced by professionals.

‘You will never – I mean, even the emotional development of children, we’ve seen, you know, really great strides within that hospice arena in terms of children’s emotional and development – every aspect of their development, which you never have the opportunity to focus on in an acute hospital environment. Not nearly enough could be provided in an acute setting.’ (FG3)

‘Well, some of those children, we would have seen very like institutionalised behaviour in the hospital. But then, you know, when they were transferred to hospice, you know, development improved greatly, but also, those behaviours stopped.’ (FG4)

‘In every way: in their posture, their ability to sit, roll, whatever, their cognitive ability because they’re getting the right sort of stimulation. It is absolutely fantastic.’ (FG3)

Whilst medical needs of the child took priority in hospital, the hospice team was able to take time to make a real difference through small but important acts for both the child and family (as evidenced below):

‘I heard the Dad going up the corridor going, “It’s amazing! He’s washed and he’s in his t-shirt!” That was what made a difference to them, and I suppose that…those sorts of things that were met…that the…the child was – and it was a young person, was an individual here, as opposed to a person in a bed in a hospital, and that made a difference’. (FG1)

‘The day that that young person came here, as the young person was being moved from the stretcher to the bed, at the same time as moving the young person, the white pillow was whipped away and the sheet was whipped away, and all of a sudden, straightaway, he looked different, and the family experience from that minute, you know, and that was done as the same transaction of the movement from the stretcher onto the bed, so it happened immediately’. (FG1)

Enabling families to be together and enjoy family time, is something that was noted as being largely impossible within the hospital environment where facilities for parents were limited and siblings were not permitted to visit.

‘You know, so they’ve got so much more, they’ve much better facilities for parents, because we have very limited facilities for parents and family here [in the hospital], which is a huge fault, you know, that we don’t have… We don’t even have, you know, overnight canteen facilities and so on, you know’. (FG2)
‘But you recognise that these children need to see their siblings, do you know what I mean, see them, and grandparents and things, and yet we know as well you can’t have them coming in constantly [to the hospital]. It’s very difficult. How do you explain to a six year old at home, you know, why their baby brother or sister, why they can’t see them, you know, and it isn’t right, you know.’ (FG2)

Contrastingly, examples were given regarding how the hospice environment could more adequately address the needs of the family unit and the child’s central role within that unit.

‘The family…the family, suddenly, siblings and everything have access to their child, you know, where, for long periods of time, especially over the winter periods with bronchiolitis, children just…they don’t get…and parents are pulled both ways if they’ve other children. You know, they’ve got a child at home that’s missing them, they’ve got a child in hospital they need to be with, and they can’t be in both places at once. They’re trying to keep paying their mortgage, keep money coming into the house – that’s a big issue. A lot of these parents, you know, financially, I feel are thrown into a very bad situation as well’. (FG4)

The confines of the hospital environment were seen as barriers to a flexible approach that promoted normality and thus enabled living life to the fullest. The physical space and facilities within hospice were seen as facilitative, as evidenced below:

‘Well, the hospice had the wee bus, the minibus, so they would just take him on the bus and… Whereas, the hospital, yes, you’d get a nurse and a carer, and you’d have to order a taxi and… But then that’s taking a nurse that’s maybe shared between six children off a ward, and what do you do to manage the staffing? It just wouldn’t happen on a ward’. (FG3)

In addition to the theme of ‘Living again’,-acknowledged by both parents and professionals, was a recognition of the important role hospice staff undertook while working with families to address both their own and their child’s needs. This helped families to gain much needed confidence in caring for their child and is captured in the next theme, ‘Learning to care’ which was seen as crucial to the step down process.

**Theme 3: Learning to care**

Learning to care was a major theme within the focus group discussions, and captured both a professional and a parent perspective.

The high dependency of the child’s needs was challenging and a source of anxiety for the staff whether that was in a children’s ward, in hospice or community setting. The children were described as ‘scary’ in the early days until staff got to know them.

‘These children are scary, they are really scary’ (FG1)
Staff in hospice reported initially feeling anxious about the technology needs of these children, but quickly gained confidence and competence in this complex care. Staff from the community in turn often came to hospice to learn more about the child and their needs. What became clear from participants was the fact that the children’s nurses found it easier to learn the skills to address the child’s specific needs than those who worked in adult settings.

“I remember the staff nurse [adult trained] coming in one day and she was watching me and she was petrified – I could see she was petrified, learning how to do suction and the trachy, and she said she hadn’t seen a trachy for years, do you know what I mean, and I think there’s that, ah-ha, things around that, somebody coming home who’s ventilated and they’re going to be responsible for them. And you could just see them…they didn’t want to…they didn’t want to take that responsibility, because whenever it’s children’s nurses coming in who are in children’s services, it’s easier, do you know what I mean?” (FG1)

“I think children’s nurses are more equipped to deal with the technology-dependent side of things than adult services maybe, albeit that they, you know, have the services in hospital, but maybe things like trachies and NG tubes are…em…something that isn’t routinely performed by the district nurse at home per se and the patient has to go back to the hospital for, and from that perspective’ (FG5)

Professionals equated ‘Learning to care’ for parents with their regaining confidence as parents again and developing the clinical skills needed to care for their child. This learning initially seemed overwhelming but with support these skills developed.

“They never saw themselves being able to change trachies and do NG feeds and do all the things that they ended up doing very capably’ (FG5)

The skill of professionals in hospice in creating a conducive and supportive environment for such facilitative learning for parents was made clear.

“So I think then the support that they got in hospice to bring them along really helped as well too’ (FG5)

Such teaching built on learning that had already started to take place within the hospital, and gradually and skilfully enabled parents to gain the necessary confidence and competence to parent their child with differing and complex needs. Staff highlighted just how individualised the teaching of parents was, and often indicated a mismatch in what hospital staff said parents could do when undertaken in the more home-like context.

‘Whenever we know that the child is coming, we’re trying to find out what sort of care they’ve been able to do, and obviously, they’re going to be trying to learn those skills and to be ready for home. So, sometimes we’re being told they’re already competent in this, that and the other, but when they actually arrive, we’re finding that that’s really not the case at all, em, and, for different parents, it’s been very much, as we said, very individually different.’ (FG1)
Participants indicated that in an acute hospital setting, the focus seemed often on demonstration of skill in each clinical task, whereas, in hospice, skills development took place in the wider context of parenting.

‘And I think, as well, the hospice look at the parenting skills, how they are as a parent, not only at how they are as being competent to deliver clinical care, and that’s a big difference…but there’s more to looking after a child at home than sucking them out, doing their physio, and doing their care. You know, it’s about…the decision-making of those parents and things, and the Hospice staff would be very clued into that side of it, whereas the hospital, it’s an acute facility, and they are focused on clinical care and that is their focus there, you know.’ (FG4)

Employing and retaining carers trained to care for the child was identified as challenging for community teams as evidenced below.

‘Like, we strive towards consistency with families at home, but with…but there is an issue in terms of our non-registered workforce that there’s higher turnover, and that’s just- and there’s nothing you can do. And some of them go off to be nurses, which is fantastic and we love to see that happening, but we lose people to that as well and so, you know, with the best will in the world, that hospice environment also has a more consistent workforce in terms of the same people and continuity, and while we really do strive for that, because we actually recruit to packages as far as is possible, but you can’t replicate that.’ (FG3)

Staff in hospice and community teams missed providing highly technical care and felt their skills were not being maintained when they did not have a child with these needs.

‘But the flipside of that is the benefit it brings to us because, right from the very first child we took for step down, we had people in the team who…had the competencies but perhaps weren’t practising all the time. They weren’t seeing the higher level skills of ventilated care. So you’d got people that could dip into it very quickly and were very capable, and you’d other people who had quite a bit of catching up to do, but what we saw whenever, em, we started step down and we had those higher level dependency children particularly the ventilator-dependent children, the benefit to team and keeping skills at a level of practice and confidence in what they were doing, … and having people to back them up, they, you know, the confidence, it strengthened that. And now, do you know what is happening now, that we are not in that situation, people are actually really missing that level of care – they’re missing that.’ (FG1)
Theme 4: Developing Partnerships
‘Developing partnerships’ between hospice and Trust health and social care staff was at the heart of providing step down care to children and families. These multiple and multi-layered partnerships were, viewed by participants as crucial for successful caring.

‘We had a need, they had a means of meeting that need, and, together, we were able to work in conjunction.’ (FG3)

‘It’s a piece of good collaborative working, and I think it just demonstrates how we can do that. Between the voluntary and statutory [services].’ (FG3)

Partnerships centred on the needs of the child and family and the 3 subthemes that gave further insight into the components of the partnership working were- ‘Organisations working in tandem’, ‘Trust and transparency’ and ‘Pushing the boundaries.’

‘Working in tandem’, with the same goals and through the same policies made the step down process much more straightforward.

‘And on the back of that, we have very good professional links with the Hospice, really good, because, when I was talking earlier about risks and risk assessment, they get it, the same as we get it. You know, they know what they're doing, they know what is expected, they know that we would think the same, and they use the same delegation framework, the same processes, as we would, and we want them to use. So, in that respect, that’s good. Yeah. They understand the community setting I think much… much better.’ (FG3)

Conversely, when difficulties were encountered and reluctance to work ‘in tandem’ was transparent, staff felt frustrated:

‘There seems to be a lot of bureaucracy in some Trusts, to a level whereby – and I know what [participant’s name] saying, they did start working in partnership with the physio, but initially, when we first started exploring this, we just came up against a brick wall and it was always people just kept throwing back resources, resources, resources.’ (FG2)

Effective partnership working enabled hospice staff to update their skills and to learn new ones as dictated by the individual needs of the child. This illustrated a ‘can do’ attitude.

‘You know, if it’s maybe something they [hospice staff] haven’t seen for a while, they’ll just… they’ll come up, they’ll get updated, and off they go.’ (FG2)

Careful forward planning was also part and parcel of successful professional partnerships as was the identification of ongoing support throughout the discharge process and beyond.

‘You know, in one particular case, that worked very well, but it’s very dependent on the whole team approach and having a process in place that’s able to take into account, you know, what happens out of hours and who you call on and what services are there to support the family because they can be very much left, you know, feeling very isolated.’ (FG5)
'That’s probably the single biggest challenge, and I think the other things come out of that, like having your agreement with the Trust and knowing that the referral is the right referral. I mean, we’ve had, em, in the last … couple of months… conversations with Trusts about two other children potentially coming here, and neither of those transpired… but one, for one child, it was because there was no plan. There was no plan, and it was…this looked like the best option, and they knew that we’d done it for somebody else. Now, we wouldn’t go into that situation because we – well, we can’t. We’re not a children’s home, you know. So, it’s being really clear about what we can do and what’s appropriate to do.’ (FG1)

Trust emerged as fundamental within successful professional partnerships and was beneficial to all parties.

‘But I think the fact that you’ve done it a few times and you know that, yes, we do that, and everybody works pretty well as a team, and the children benefit, the families benefit, and the staff benefit too, you know.’ (FG1)

‘Trust was tested if transparency was not obvious. For example in situations where staff felt that the child was being passed to hospice, just in an attempt to move the child on and free the bed.

‘Mm, whereas, in hospital, it was, you know…it wasn’t seen to be an appropriate setting for him and he had to go, you know, somewhere else – he couldn’t stay there.’ (FG5)

Trust also resulted in reassurance for professionals that others were there to support and that no one professional or organisation would be abandoned.

‘And I was glad of [the support] too and quite happy then to cooperate and be flexible, and probably that way of doing things might lead to more flexibility and cooperation from general practice because you’ve got past that initial fear that this is a one-way process that’s coming, a one-way train that’s coming your way, whether you want it or not, you know.’ (FG5)

Clear open communication was also essential. Staff highlighted the importance of transparency about roles and responsibilities for each party-the hospice, the Trust and the HSC Board.

‘It’s the Trust’s responsibility and it’s the Board’s responsibility, and [hospice] can support them and we can provide care and we will push the boundaries, but it’s not our responsibility. We have a responsibly to contribute towards it but… and it’s holding that line with people, em, and we need to do that. If this is going to be….if there’s going to be any infrastructure around this, and if this is going to be something that is planned on a regular basis for an identified group of children, there have to be processes around it that are recognised.’ (FG1)

Further, it was also obvious that partnerships developed from a bedrock of highly committed staff who pushed the boundaries to ensure the best care for the child and family. Professionals in such cases went that extra mile in terms of their role.

‘There was a consultant respiratory physician who was very, very good as well, who was coming out to the house, which was probably not really within her remit.’ (FG5)
Theme 5: Best place, best care

It became apparent throughout professional discussions that step down care provided by children’s hospice was greatly valued by all those who had experience of it and such experiences highlighted ‘lives transformed’ for children and their families. Professionals recognised hospice provided a safe environment that nurtured parents and built their confidence in the care of their child resulting in the belief that the hospice was the best place with the best care for these children.

‘Best place for them, where they’re going to be able to get the care that they require, but they no longer need to be in any hospital environment, so actually, it’s preferable, and it frees up the beds for someone else who’s acutely ill who requires it at that point in time. So, I think that’s a definite benefit.’ (FG2)

‘But the experience to date has been really, really positive for the Trust, and I would say for everybody, you know, and for the families, it’s been exceptionally good.’ (FG4)

Whilst hospice is recognised as ‘best place, best care’, a number of subthemes arose from this theme contributing to such best care but also recognising the limitations and making suggestions for future developments of this service.

Benefits of the Service

Benefits of this step down service were clear across all groups as evidenced throughout the other themes and were brought together here. Allowing children to ‘live again’ in a homely environment with skilful professional support for their care needs alongside the needs of their family was pivotal to the care offered by hospice (See summary below).

Table 10: Added value of hospice as location for step down care

<table>
<thead>
<tr>
<th>Child</th>
<th>Family</th>
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</thead>
<tbody>
<tr>
<td>More stimulating environment</td>
<td>Confidence building in safe environment</td>
</tr>
<tr>
<td>More space</td>
<td>Gentle transition to home</td>
</tr>
<tr>
<td>Time for more personal/holistic care</td>
<td>Promotes family togetherness</td>
</tr>
<tr>
<td>More homely environment</td>
<td>Support/individualised</td>
</tr>
</tbody>
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The skills and knowledge of staff in hospice was central, in that their experience was built on caring for children at the end of life, enabled them to respond and react to need with urgency and efficiency.

‘I think our experience in end of life care is very, very important in what we provide in step down care because our skill in end of life, that ability to connect to the family, that ability to assess frequently what they need, and the flexibility in the care that we provide.’ (FG1)

‘Obviously, there’s a lot of experience there that is associated with them doing end-of-life care, but that…that type of, em, approach lends itself very well to that type of work that is needed, the intensity and that engagement.’ (FG3)

‘I think the expertise of the Hospice and their way of dealing with it was very fortunate for the family and the child.’ (FG5)
The environment also had an important part to play also shaping such good practice.

‘I think also that is an incredible environment, and I’ll touch on what [participant name] said there: there’s a calmness and there’s a peacefulness around the Hospice environment and indeed the staff that work within it, in terms of how they deal with people and how they approach people.’ (FG3)

The hospice’s ability to systematically plan and organise care was also highlighted as a strength, something that came with their particular experience and expertise. Such attention to detail was compared to the often lack of organisation experienced when discharge took place directly from hospital home as articulated below.

‘Though I think, in some ways, maybe because it was the hospice, that it actually went well, because I was impressed with the organisation of the meetings before the patient got out because I don’t recollect that sort of thing happening in my experience in the more acute setting in hospitals. There’s an awful tendency – GPs would moan about this – that the patient is home before you know it and you get the letter, you know.’ (FG5)

**Limitations of present service**

Notwithstanding the overwhelming benefits of hospice as ‘Best place, Best care’ there were limitations identified of the current service and a sense of frustration on the part of professionals who felt hospice was the best place but that the availability was so limited.

‘Well, I, personally speaking, couldn’t speak highly enough of the Hospice. I…it’s a fantastic place for the families, for a start, and the staff there are second to none – you know, couldn’t speak highly enough of it. The problem is that there’s not enough of it.’ (FG2)

There was also an awareness of the impact on the other hospice families if a child was in long term for step down and this was seen as a restrictions or knock on effect of step down care as clear below.

‘As we stand as a service at the minute, the impact of that is that our provision for respite is affected. So, while you’re very willing to take this care and see the benefit of this care for that family and all of that, in the back of your head, you know, right, we’ve lost a bed, and you know that probably, phew…two or three families a week will be affected by that, and over the course of four months, you know, it’s not long before you’re mounting up, the other…the number of other people that are affected by that situation. But that’s on a very practical level.’ (FG1)

‘The hospice, they’re…they’re limited in what they can offer at the minute, em, and…so we can’t really use them as a step down service for a prolonged or an indefinite period of time. So, they help us out with respite but em…they have, in the past, helped us out on a longer term basis, but then it’s…em…for their other residents, it makes it a bit harder to take in other kids.’ (FG2)

Whilst the benefits of hospice care along with the restrictions on availability of the service have been articulated, discussions continued by proposing the direction for the future service in the final subtheme.
Theme 6: The Future Service
Professionals talked of the need for a more definite arrangement in the future, when preparing for home and for continuing support when discharge home has been achieved. They acknowledged that there will always be a small group of children with most complex needs requiring intensive support to live at home and therefore a strategic approach to how their specific needs will be met is required.

‘The ideal position in relation to this cohort of children would be have…would be to have increased respite facilities, opportunities for step-down, and also opportunities for long-term care if that’s required, and if it all could be in an environment, one environment, it would be even better because you’d be building on a skill set that already existed.’ (FG3)

‘It’s obviously something that we’re looking at all the time, you know, even if we’re looking at [a] new hospital, new children’s hospital here, would we have a dedicated step down area, is that actually what we need, step down from one bit of the hospital to the other – is it really that beneficial? There’s a difference between HDU and ICU, and that’s a whole different thing, but really about that…if they’re medically fit to go home, you know, what’s the point of moving them into another unit in the children’s hospital? It’s just part of the children’s hospital and looks like the children’s hospital. You want it to be more home from home at that point. So, I could see there would be a huge benefit if you had, and it might actually ease it for parents if you could call it, you know, this is the step-down part of the Hospice, where it’s the Hospice but there are dedicated beds for this purpose.’ (FG2)

The implications of establishing services for a very small number of children (in service planning terms) from different regions of Northern Ireland were also considered.

‘Northern Ireland isn’t a big place and, in any situation, you’re never going to suit everyone, you know, and it’s like [people wanting their] local hospital at [their] front door, you know–there’s always going to be people who are going to have to travel a distance and that’s just part of life. But at least if it is a facility that’s child friendly and geared towards children, you know, these children with particular difficulties and families, well then it has to be better than…than any hospital, you know’ (FG2)

‘Taking it a step up just even from a strategic perspective, em our reliance on the children’s hospice has always been because we do not have any type of purpose-built facility to facilitate either long term respite or step down or transition, and in terms of that, I think that we have, we have heavily relied on the hospice and we have had a wonderful service from the hospice, and indeed it has been the only place fit for purpose in terms of meeting the complexity and risks associated with caring for that group of children.’ (F3)

Staff also reflected the reality that what is being expected of parents is at times, too great and that for some children, the goal of transfer to home is not achievable. Alternate locations for longer term care therefore need investigated.
‘…and I think the point [participant’s name] was making earlier on about “what are we doing? What are we expecting of parents” there’s some children [that come out] that it would be extremely difficult to care for for a month, let alone two or three years or [a longer] period, so whether we are looking long term at some form of residential care.’ (FG4)

‘I mean, you will just have parents saying to you “I can’t do this anymore” you know…they just don’t want people in their house any more.’ (FG4)

The emotional and psychological load that builds on families caring for these children and the potential for families to hit crises was acknowledged. Hospice was seen to be a critical service at such times as it had the capacity to respond and to admit the child, however, with knock on consequences.

‘…we hit crisis point with these families and I must say the hospice [has] been superb in helping us with these…now I don’t think they are in a position where they can do that so much…because it means that every time we have a crisis and we’re putting somebody in there for two or three weeks, then that cuts down on what they can offer to other…other families, you know.’ (FG4)

Discussions also reflected on the emotional demands on hospice staff generated through ‘caring in a different way’.

‘One thing that I am really conscious of, going forward, because I think we are committed to doing this but I know the cost for people has been difficult, and if we continue to do this there’s going to be more of that. It’s a different type of relationship you have…emotionally, emotionally…in terms of a child being here all day, every day is different to say, maybe having a very intense relationship with a child you see this child now, and then you see them again, and then at a later point, and I think that is just something I’m mindful of in going forward because it may mean we need to do things a little differently in terms of staff support.’ (FG1)

‘I think that is a whole new…that’s a whole new area for hospice staff…We’re acutely aware of that because it is the whole attachment side of things because they…their bread and butter in the past has been end of life care, but its nothing like the attachment they have in these types of situations.’ (FG3)

‘Yeah, because they’re not just caring for them, they’re caring about them and that brings a different dimension to it.’ (FG3)

Careful consideration will be required to identify appropriate methods of staff support, not only in the hospice but in hospital or other settings where children are residing for prolonged periods of time.

Strengthening the medical support provided to children receiving step down care in the hospice was proposed as one area for future attention.

‘I think one of the issues would be maybe medical…. You know, it’s probably more the hospice’s problem than ours, but who takes medical responsibility?’ (FG4)
This discussion thread related to the current processes whereby a child being discharged from the tertiary centre may be transferred to the care of a local paediatrician who is then expected to contribute to the oversight of their care in the hospice although they may have not “really know them”.

Cost was a potentially prohibitive factor to accessing step down care in the hospice.

‘The cost…it’s the cost of getting the money to… to buy the service.’ (FG4)

This was balanced though with the acknowledgement-

‘It is an expensive service, but it would be expensive wherever it was coming from.’ (FG4)

From the hospice perspective, recruitment was considered a real challenge to being able to offer step down.

‘The staffing is probably the thing-you know, its not the money…Its actually getting the recruitment to the level that we can do this without making the rest of the service vulnerable.’ (FG1)

There was a genuine concern for sustaining step down as an ad hoc service through the use of a core service bed.

‘While step down is really important and we know that we can do it, where absolutely, where possible, that needs to be something in addition that we do, rather than instead of, because if we diminish the rest of the planned stays for the families, we’ll become irrelevant to them.’ (FG1)

‘I think we need to keep working internally, but we need to be working externally with the Trust and with commissioners because, em, anything we do has to be part of a wider process for this group of children.’ (FG1)

In conclusion, the consensus opinion across the focus groups was that this group of children required a service provided in accordance with the model in place in Northern Ireland Children’s Hospice. Indeed, there was recognition of the merit of Northern Ireland Children’s Hospice considering its capacity to be the provider as an additional service to their core model of care. However, the capacity to sustain this in its current form needs careful consideration due to the negative consequences generated for families availing of core hospice care. It is therefore necessary for all parties to continue pressing for a strategic approach to planning to meet these needs.
Phase 4: Exploration of costs of care across settings.

The identification of costs proved to be an inexact science and reflected the challenges experienced in other children's hospices presented in phase 1 above.

In this phase, the costs for step down care relating to the child in Northern Ireland Children's Hospice at the time of data collection were analysed across a 4 month period and then re-calculated to estimate cost of care per bed night. Data was requested through the finance team and by reviewing the monthly budget expenditure reports to capture:

- % salary costs allocated to the child's care across the professional, administrative, catering and housekeeping teams
- % general medical supplies (e.g. wipes, soap, sterile water, tissues etc) and clinical waste costs allocated to the child calculated at 1/7th total (7 beds funded at time)
- % overhead costs

This generated an approximate figure of £647.00 per day\(^4\). Child specific supplies—trache tubes, ventilator circuits, pharmacy, feeding supplies etc were funded and supplied by the HSC Trust in which the family resided. Figures supplied by the Trust through a review of the child's cost centre indicated an average monthly cost of £1900.00 or £63.33/day (30 day month) inclusive of ventilator hire costs but excluding specialised equipment such as electric wheelchairs and seating/bathing aids. HSC Trust staff costs associated with the support and therapeutic intervention by community nurses, nurse educators, social workers and allied health professionals are also not reflected in this figure but need to be considered as they make a considerable and on-going contribution to the child's care.

Comparative hospital costs for approximately the same time frame were not possible to source as the most recent available data related to the financial year 2011-2012. These figures identified the cost of a paediatric intensive care bed at £2027/night and a paediatric medical bed at £828/night. Whilst hospice provided step down care does not equate with intensive care, the staffing and skills level is greater than an average medical ward due to the complexity of the child's care needs along with the specific risks resulting from such needs. In addition, the provision of single bed rooms for all children and the fact that the child will move from a single location (i.e. a hospital side room) around the hospice and indeed out of the hospice requires a staffing ratio of 2 highly skilled members of staff per child. Anecdotal discussions with hospital nurse managers indicated that, in reality, the additional needs and staffing requirements these children generate within a medical ward often results in a reduction in beds to increase the staffing complement for the child. The average cost per night therefore is an under-estimation of the true costs of caring for these children within a medical ward environment.

\(^4\)This is less than the £750.00 figure quoted in Table 6, Phase 1. The child had been participating in step down care for 9+ months and some staff related costs (e.g. involvement of the education team) were reduced. The charge to the Trust reflected this position.
A literature review was undertaken in an attempt to identify assessed costs for similar services across the UK. Little information was available and in the few reports providing costs, comparison was made between hospital and home-based care (WellChild/RCN, 2009). The NHS Confederation (2009) in their report “Aiming High for Disabled Children-delivering improved health services” included reference to children with most complex needs remaining in hospital for prolonged periods of time. Comparison was made between the cost of high dependency level hospital based care (£1.5-£2.5k per night) and the transitional service provided by the Children’s Trust, Tadworth where costs of care (2009 rates) were reported at £1.3k per night inclusive of therapy, leisure and education activities.

The great disparity in costs between hospice based step down care as reported in phase 1 of this study and the Children’s Trust likely results from an under-estimate by hospices of the actual additional costs of care should step down be established as a discrete service. These children are the most complex and most clinically vulnerable. Their presence increases the dependency levels of children in the hospice at any point in time, bearing in mind that children supported through invasive ventilation or with similar level of needs are admitted to hospice for short breaks, not to mention the on-going presence of children requiring symptom management or end of life care. A shift is therefore required in the skill mix within the staffing complement across the 24 hr span to increase the number of registered nurses and non-registered, but highly skilled staff competent in the advance care needs these children require. Access to physiotherapy-historically in many hospices a Monday to Friday service, will need to be considered for weekends and periods of annual leave. Simply calculating the daily costs of a child requiring step down care is therefore not a true reflection of the overall costs establishing such a service will incur.

It is also unlikely that most children’s hospices will consider employing speech and language or occupational therapists with this support instead ‘in reaching’ as part of the collaborative agreement with the Health and Social Care Trust in which the child resides. This has been a viable option in Northern Ireland as the children’s families resided in Trusts located close to the hospice. Community children’s nurses and social workers allocated to the family will also fulfil their responsibilities at a higher intensity to what they would provide if the child was at home while they complete assessments, deliver training and participate in review meetings. These costs also need considered when calculating the ‘true’ cost of care.
Synthesis of the findings across the four phases generates a number of issues should commissioners and service providers across the statutory and voluntary interface wish to consider the establishment of a transitional model of step down care within a children’s hospice environment for a cohort of these children.

1. **Valued service**
Firstly, parents, professionals and hospices consistently voiced their view that step down care provided in a hospice environment was greatly valued. Families and professionals across hospital and community settings acknowledged that hospital was not the place for children once clinically well, and that it was in fact detrimental to their well-being. Children who experienced step down care in the hospice were noted to have improved quality of life and quality of experience and their development progressed rapidly in the more home like environment. Families had the opportunity to be a family again. Special note must be made of the reality that many young children will have been in hospital since birth, posing challenges to parent and sibling bonding and restricted opportunities for wider family members to visit the child. The adjustment in the power relationship between parents and clinical staff once transferred away from the medical environment, coupled with the supportive and constructive challenging techniques inherent in staff skilled in palliative care facilitated parents to be parents again and to develop the care competencies their child required. Financial costs to the family reduced, as car parking charges are no longer incurred and meals are provided within the hospice model of holistic support. Statutory services found in the hospice a workforce skilled in the competent care of the child and a pragmatic but rigorous approach to risk management. In the hospice, robust preparation could take place for transfer to home. Effective partnership working between organisations enabled both to fulfil their obligations and responsibilities. Frequent monitoring and review meetings enabled progress to be tracked and action taken swiftly to address emerging difficulties. Hospices responded collectively that they were able to provide ‘something good’ for children and families. The presence of a child receiving step down care enabled staff to maintain higher level care competencies associated, for example with the care of ventilated children. On-going communication between community teams and hospital staff, especially consultants and lead nurses nurtured relationships and raised the hospice’s profile.
2. What was reported to work well
A number of factors were considered to aid the step down experience for families and the processes for the organisations involved as outlined in Table 11.

Table 11: Factors that aided the step down process

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<th>Factor</th>
<th>Additional information</th>
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<td>Realistic discussions with clear expectations.</td>
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| Set criteria to include-                        | • Confirmation that the child was medically stable and considered to have a stable airway  
• Assessment that the child’s needs could be met by the hospice without compromise to other children present  
• A clear plan for transfer beyond the hospice  
• Clear lines of medical responsibility, quick access to consultant level specialist advice and transfer plans to hospital if the child became unwell  
• Agreed roles, responsibility and accountability between the statutory service and the hospice. This included such matters as honorary contracts for statutory staff being trained on site, the role of clinical educators from both services, agreed competency frameworks for training parents and staff, and confirming which organisation held responsibility for deeming parents competent.  
• Ongoing, effective communication pathways and regular meetings for monitoring, problem solving and review. |
| Skilled introduction of the potential of hospice was critical by a professional known to the family. | Encouraging families to be open-minded until they had visited the hospice helped families inherently resistant to using hospice services due pre-conceived notions that they are services for dying children. |
| Ongoing support for the children and families.  | The emotional load on parents and siblings is immense. While hospice was seen as a positive stepping stone from the alternative of remaining in hospital, it was not home and remained disruptive to normal family life. Life had changed for the family and while receiving step down care in the hospice, the new reality of integrating the child with most complex needs into their family along with an intensive package of support had yet to be tested within the home setting. Access to psychological/psychosocial support needs to be considered in the development or provision of step down care. |
3. Specific issues for children’s hospices.
Evidence from this study supports the proposal that step down care has the potential to be an appropriate and beneficial service within a children’s hospice model of care, where capacity exists (i.e., where hospices have beds that have not been opened). The current ad hoc response is not sustainable due to the pressures placed on core services and staffing levels. Developing step down as a discrete, permanent service, with full costs secured through commissioning strands is recommended as the sustainable approach. This will enable the overall staffing complement to be increased accordingly. (Staff members, it is proposed, should work within one collective team rather than establishing a team for core hospice services and a team for step down.) Further work will be required to identify how funding will be secured, the commissioning arrangements and ‘ownership’ of the bed, thresholds for access etc. It is proposed that children with most complex needs could be prioritised for additional short break care during periods where this bed is not allocated for step down care.

4. Funding
Participants in this study indicated a belief that step down care costs set by the hospice were considered expensive and a potential obstacle to its use. Wider exploration of costs of care confirmed that the care of this group of children is expensive, regardless of the setting and Northern Ireland Children’s Hospice costs are at least comparable with hospital based care and are on a par with other hospices across the UK.

5. Strategic issues
Whilst the number of children and the level of complexity of their care will vary across years, these children and families will continue to constitute a discrete group with specific needs within our population. Transition from the hospital environment should be progressed much quicker than at present. The merits of an alternative location have been outlined above. In Northern Ireland, as in other regions across the UK, economies of scale make it unrealistic to consider at this time the development of a stand-alone transitional service. Children’s hospices may be ‘fit for this purpose’ on a number of parameters-
- Their ethos promotes whole family care, prioritises quality of life and experience and maximises the potential for child development and family support.
- There is a history of effective partnership working with statutory services. (In Northern Ireland, this is strengthened by the hospice providing a regional service).
- Their corporate and clinical governance structures effectively manage risk and provide safe care.
- Their workforce possess the clinical and psychosocial skills children and families require.
- Their ability to establish step down care while protecting core services (where additional capacity exists).
The establishment of a transitional step down service cannot be viewed in isolation but must be integrated into efficient discharge pathways. This will be achieved in Northern Ireland through the implementation of the Regional Discharge Plan (PHA, 2013) which will ensure effective and consistent processes are in place and will monitor for unexpected delays. This in turn will give confidence to the planning process should children be transferred to the hospice and will promote effective use of the step down bed(s).

Commissioners and service planners must also consider the on-going demands on families caring for children with most complex needs at home. Regular access to short breaks outside of the home must be built into support packages. Account also needs to be taken of the reality that for some children, long term care arrangements will be required outside of the family home. Securing foster placements or adoptive families for these children is close to impossible with a residential facility being the remaining option. This is a separate issue to transitional step down services although confirmation that transfer to home is not possible may only emerge during step down care.
The following recommendations are proposed.

1. A child and family centred approach which recognises the psychological, emotional, social, and spiritual needs of the child and family as well as the medical needs of the child should be adopted to ensure that children are cared for in the most appropriate setting to address their holistic needs.

2. Children who are considered ‘medically stable’ should not remain in an acute hospital setting for any longer than clinically necessary. Transfer to an alternative environment should take place as soon as possible once the child is considered medically stable and in line with guidelines established in Discharge Plans or pathways.

3. The potential for children’s hospice’s to provide an alternate setting for care within a ‘step down’ model should be considered where-
   a. Children’s hospices determine they have the capacity to commit to providing such a service on an ongoing basis where they are not currently utilising all available beds.
   b. Children’s hospices consider it appropriate to extend their model of service provision, and their statement of purpose to incorporate step down care through agreement with the Regulation and Quality Improvement Authority/ Care Quality Commission or similar agencies.
   c. Further discussion and planning across the key commissioner, statutory services and hospices establishes a pathway in which this model of care could be established, monitored and funded.
   d. Funding arrangements are agreed to cover full costs of designated step down beds to enable hospices to make the necessary adjustment to its workforce.
   e. Processes are agreed to promote effective use of the step down service to include-
      i. Referral criteria
      ii. Partnership working practices and lines of accountability
      iii. Timely transition pathways to home (or an alternative location when transition to home is not possible)

4. The ongoing need for regular specialist short breaks out of the home should be considered and incorporated into agreed packages of care to sustain families involved in caring for children with most complex physical healthcare needs.

5. Strategic consideration should be given to how the needs of a small number of children will be met when care at home is not possible. This needs to include options for residential care as well as fostering and adoption. For some families of children with most complex needs, the option of ‘shared care’ should also be considered and built into the service planning process.

6. The transition of young people from hospital to home requires specific consideration where adult community health and social care services will be co-ordinating their care.
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