

**REVIEW OF PAEDIATRIC HEALTHCARE SERVICES IN NORTHERN IRELAND (PHASE 3):**

**CONSULTATION RESPONSE QUESTIONNAIRE ON A DRAFT REVIEW OF CHILDREN'S PALLIATIVE AND END-OF-LIFE CARE**

You can respond to the consultation document by e-mail, letter or fax.

Before you submit your response, please read Appendix 1 about the effect of the Freedom of Information Act 2000 on the confidentiality of responses to public consultation exercises.

Responses should be sent to:

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**Responses must be received no later than 28 March 2014.**

I am responding: as an individual

on behalf of an organisation **Yes**

(please tick a box)

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## **Draft Review of Children’s Palliative and End-of-Life Care in Northern Ireland**

Together for Short Lives welcomes the opportunity to respond to this consultation. We are the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them. We support families, professionals and services, including the Northern Ireland Children’s Hospice (NICH).

**Q1. Does the scope of the information detailed in the review provide a comprehensive assessment of the needs for paediatric palliative and end-of-life care over the next 10 years? YES/NO**

Yes

**Q2. Are the enablers for change detailed for these services appropriate or do you feel there are others? YES/NO**

Yes. Together for Short Lives welcomes the consultation document and its recommendations. We call on the Department for Health, Social Services and Public Safety (DHSSPS) or the Health and Social Care Board to ensure an implementation plan with measurable outputs, outcomes and clear timescales supports the strategy which will come result from this consultation process. This would provide clarity for children who need palliative care and their families - and make sure that there are clear expectations and lines of accountability for commissioners and service providers in implementing the recommendations.

Voluntary sector providers (including the NICH) should be involved in any work to develop electronic care records. Only by doing so will care become more integrated and co-ordinated for families.

Too many services and professionals do not communicate properly with families or each other, which can have significant adverse outcomes for families. Some parents speak of their child being given a diagnosis with little factual information and not being helped to understand what this means for the child and the family. They also speak of being given inaccurate information - or important information being given to them insensitively. To address this, we call for the ‘Breaking Bad News’ guidelines to be implemented fully.

**Q.3 Are the 18 recommendations appropriate or do you wish to add or remove any? YES/NO**

Yes

Together for Short Lives believes that all the 18 recommendations, if implemented fully, would make a meaningful difference to children with life-threatening and life-limiting conditions and their families in Northern Ireland.

In implementing the strategy, it will be important that additional funding is made available to make sure that all the recommendations can be implemented. In particular, it will be important that children with life-threatening and life-limiting conditions can access multi-disciplinary assessment and community services at any time of day or night. This is not currently the case in Northern Ireland and funding will need to be identified to rectify this. Such investment would be cost-effective: where a child and their family choose to receive their care in this setting, comprehensive children's palliative care services provided in the community ensure better outcomes and reduce the risk of an unplanned admission to acute care.

### **Recommendation 1**

We fully support this recommendation and reiterate that effective communication will be critical in realising it. Families emphasise care and support options, open and timely discussions and involvement in decision making as critical elements. Communication skills should be a part of training for all professionals. If communication is handled badly the effect can be devastating for families.

### **Recommendation 2**

We fully support this recommendation. It is critical that families have access to both planned and emergency short breaks both within their home and in other appropriate settings. Families report that the ability to choose has a positive impact on their lives. We call for flexibility to meet children and families' changing needs.

Young people going through, or who have gone through, transition from children's to adult's services emphasise the need for age-appropriate short breaks and work opportunities.

Extended or intensive short breaks should be provided for children whose needs are particularly complex and for families whose capacity to continue caring for their child is limited for whatever reason. A child in Northern Ireland with complex healthcare or palliative care needs who cannot live at home currently has no alternative care setting outside of the acute hospital setting.. The NICH, as an established provider of specialist short breaks both in Horizon House and in the child's own home, is well placed to contribute to service planning and design at a regional level.

### **Recommendation 3**

Together for Short Lives fully supports this recommendation. We emphasise

the importance of a comprehensive multi-disciplinary and individualised assessment of need and for this to be reviewed regularly.

#### **Recommendation 4**

We fully support this recommendation. Parents should have planned opportunities to participate in regular multi-disciplinary reviews of their child's care needs. Reviews should take place at least annually, even if a child's condition appears to be relatively stable. NICH staff should be included in multi-disciplinary reviews for all children using hospice services.

Families' resource needs, which might include wheelchairs, specialist beds or housing adaptations, should be identified as early as possible. The Health and Social Care system should help to make sure that resources are provided where a need is identified.

#### **Recommendation 5:**

We recognise the need for 24/7 community services to be in place to support families caring for their child at home. While this has a particular focus within the Phase 1 and 2 of the review, it also needs to be considered in the context of this review. In order to make an effective and comprehensive palliative and end of life care service available to families, nursing and other community resources must be available 24/7. Families report that without this, their children do not have access to care at critical times. Some families report feeling guilty when professionals support them in their own time and lead to them being reluctant to ask for help - even in desperate situations. This should not be the case: children should have access to the right care at the right time and in the right place, regardless of time or day.

#### **Recommendation 6:**

We believe that identifying a keyworker is critical for a family of a child with a life-threatening or life-limiting condition. We therefore fully support this recommendation. Families tell us that too often they have to explain their child's condition again and again to professionals, which can be traumatic. Having access to a keyworker would help to address this. Families feel that a keyworker should be in place from the point of diagnosis or recognition. Identifying one person as keyworker and who can then coordinate the communication with everyone else would make a real difference to families. Where a child's condition is very rare, one of the multi-disciplinary team should have responsibility for learning about the condition and disseminating the information to the family and other professionals. Families want health and care professionals to be well briefed about a child and their condition before they meet with families.

In addition to the keyworker role, parents feel that an advocate would be extremely beneficial to them. They would value someone who could make their case alongside them and alleviate some of the pressure of needing to fight to have their child's needs recognised - and get the appropriate support

put into place.

Young people who are going through or have gone through the transition process emphasised the critical nature of the keyworker role throughout their lives - and particularly at transition.

The NICH could appropriately fulfil the keyworker role for some families.

**Recommendation 7:**

We fully support this recommendation. We are very clear that better planning for discharge from hospital is badly needed so that children do not stay in hospital longer than they need to. Appropriate care options need to be in place for those children who cannot live at home and for whom there is no clinical need to be in hospital.

Parents agree that a transition or discharge plan needs to be in place. More importantly, one individual needs to ensure this plan is implemented is located in each hospital. Parents stress that there should be two strands to transition or discharge planning. The first focuses on the child who is recovering and who needs an appropriate, timely discharge plan. This plan should meet the child's need rather than the demands of the hospital. The second strand should relate to end-of-life care. Families who have spoken to NICH cited experiences of children being moved from ICU to a general ward to die. Some examples were shared of a parent accompanying their child from ICU to be told that the ward was not ready for them yet. This should not happen.

Where plans are being put in place for end of life care in hospital, families should be made aware of hospice care as an option.

**Recommendation 8:**

We fully support the recommendation that such a protocol be developed. All groups of parents felt this was hugely important. If at all possible the child/young person should be included in the planning for the end-of-life care. Parents say they should be included in all aspects of this planning. Parents, particularly those whose child had died, felt very strongly that every family should be given information about hospice services early, and also that hospice should always be offered as an option in end of life care planning. Families reported that sometimes it appears as if professionals are uncomfortable about starting or participating in conversations about end of life care or the fact that the child may be dying. This was attributed to possible feelings of failure on the part of the professional, or to professional competition. Parents were clear that while these feelings might be understandable the focus at all times needs to be on the needs of the child and the wishes of the family.

The Scottish Government document 'A Framework for the Delivery of Palliative Care for Children and Young People in Scotland' (<http://www.scotland.gov.uk/Publications/2012/11/8118>) would make a useful

contribution to the experience of families in need of rapid transfer for end of life care.

**Recommendation 9:**

We fully support the recommendation that all young people who transition to adult services will transfer to the most appropriate service based on assessed need. Transition remains a major concern for young people and parents alike. Young people believe that there needs to be a directive for adult services to engage early and fully in the transition process. Families state that worry about the future is a real burden for them. There should be age appropriate care for young adults who transition from children's services. The needs of young adults should be considered when planning services - particularly those with limited cognitive or communication ability.

NICH has played a significant role in raising awareness of the issues young people and their families experience and employs a Specialist Transitions Nurse. NICH is currently piloting a transition project and is well placed to continue to contribute to key strategic processes in relation to improving the transition experience for all young people and their families.

**Recommendation 10:**

Together for Short Lives fully support this recommendation and believe it has a key role in facilitating this process for some families.

Parents report that they have felt terrified at the thought of needing to make such plans. However, they recognise that it is better to have time and space to think through what they want and what will be in the best interests of their child and family. Families need these plans to be created in a way which gives them confidence that they can change their minds at any time - and that all those who need to have this information will have it when it is needed. Those parents who had completed an end of life care plan felt it was very positive to have their wishes discussed and recorded at a time when their child was well rather than in emergency situations.

There is much anecdotal evidence from families who say that the death of their child was less traumatic because they were actively involved in planning their child's end of life care - and because those plans were carried out.

**Recommendation 11:**

We cite NICH's experience of supporting bereaved families, which emphasises how significant this recommendation is. Where possible, the need for bereavement support should be anticipated and families should be given opportunities to receive pre-bereavement support. Families who have continuity of care through the death of their child and into bereavement acknowledge the benefit of support being provided by someone who is known to them, and the 'freedom' of not having to constantly re-tell their story. Families report that the NICH model of bereavement care is very beneficial because it is provided by someone who knows them and who knew their child - and also because the relationship with NICH doesn't end at the time of death

and continues for up to two years depending on individual need.

**Recommendation 12:**

We support the establishment of a formal network. Existing models in Northern Ireland and the UK should be considered with reference in particular to the UK Children's Palliative Care Networks. Parents welcomed the potential for a Network to enhance knowledge, good practice and systems - they referred to not 're-inventing the wheel'.

Children's palliative care networks across the UK work in different ways but all bring together professionals and organisations from across the children's palliative care sector, and other stakeholders, to work together in a co-ordinated way, cutting across organisational boundaries. They play a key role in planning and delivering equitable and high standards of care, support and services.

Jointly developed with local authorities and children's trusts, networks can be an effective model of providing services. Regional networks drawing together local networks can provide strategic leadership to enable services to be operationally relevant and efficient.

Strong networks lead to improved services and care for children and their families - including stronger, more effective partnerships between providers and commissioners. Children, young people and families also have more say in how services are developed to meet their needs, and there is greater choice for end of life care.

A directory of local networks is available from the Together for Short Lives website at <http://bit.ly/O2kYMC>

**Recommendation 13:**

We fully support this recommendation and regard it as being central to effective medical leadership and governance. We acknowledge the impact as outlined in the review (6.1.14) of not having a dedicated children's palliative care consultant in Northern Ireland.

**Recommendation 14:**

We fully support this recommendation. Parents further recommend that there should be a lead professional based in each hospital with specific palliative care knowledge, training and experience. Within each hospital there should be a person responsible for ensuring that the overall structures are in place to deliver appropriate palliative care services and have the authority to hold people accountable.

**Recommendation 15:**

We fully support this recommendation. There needs to be a clear and

meaningful educative input for all health and social care professionals at both pre and post registration levels. Families emphasise that they need to have confidence that those assessing the needs of their child and responsible for caring for them having the knowledge, skills and experience to do this effectively. They also say that professionals should feel confident in their capacity to respond rather than feeling that palliative care is an added complication they have to deal with. Parents also emphasised that advanced communication skills should be a key element of training for professionals in palliative care.

Training should include an understanding of the role of hospice leading to a greater confidence in making this available as an option for families, and more appropriate referrals to hospice services.

As the only dedicated, regional palliative care provider in Northern Ireland, NICH is in a unique position to contribute to a range of initiatives relating to this recommendation.

Together for Short Lives believes the workforce required to provide children's palliative care in Northern Ireland includes:

- specialist palliative care practitioners from all professional backgrounds such as nursing, counselling, psychology
- non-specialist practitioners working within palliative care settings such as allied health professionals
- non-palliative care workforce who may be specialists in their own field and who deliver palliative care within their own scope of practice.

It will be important to make sure that the learning and development needs of these groups are met. Education should include flexible learning pathways, competence based education and informal work-based assessment.

We would like to bring to DHSSPS's attention the following two competence frameworks which we believe should be considered in developing an approach to education and training for the children's palliative care workforce in Northern Ireland:

- The European Association for Palliative Care Core competencies for education in Paediatric Palliative Care, November 2013 (<http://bit.ly/1jC8sSI>)
- Royal College of Nursing competences: Palliative care for children and young people, 2012 (<http://bit.ly/1gIGEtV>).

A competence framework describes the range of knowledge, skills and performance levels required of nurses working in a specialty, to help them achieve safe, effective and accountable practice. They support the delivery of high quality, evidence-based care by nurses and health care support workers



involved in the care of children and young people requiring palliative care.

**Recommendation 16:**

Together for Short Lives recognises the challenges many parents face in meeting their children's complex needs. As such, we fully support this recommendation. Parents report delays in having training provided for them and for others providing care for their children at home and this often results in significantly delayed discharges from acute settings.

**Recommendation 17:**

We welcome and fully support this recommendation. Without an accurate database it is not possible to plan, deliver, or commission services in an effective, timely and cost-effective manner.

We bring DHSSPS's attention to a research project recently developed by Professor Myra Bluebond-Langner (True Colours Chair in Palliative Care for Children and Young People, Institute of Child Health, University College London) and Dr Lorna Fraser (Anniversary Research Lecturer, Department of Health Sciences, University of York). This has been designed to help reach a better understanding of the needs and services currently available in the palliative care sector for children and young people with life limiting illnesses. The project will also examine what will be needed in the future. The project aims to:

- provide a comprehensive and detailed mapping of paediatric palliative care services in the UK
- conduct a prospective study of the way in which palliative care services are used by children, young people and their families
- develop a methodology to accurately identify the number of children and young people in UK with life limiting conditions, their diagnosis and disease status.

**Recommendation 18:**

We welcome and fully support this recommendation. A single regional commissioning lead and a separate service specification would raise the profile and status of children's palliative care and set a framework within which services can be delivered in a joined up way.

Commissioning needs to take account of those children with the most complex needs, those children who need intensive, extended short breaks or shared care arrangements, and those children who cannot live at home for whatever reason.

Commissioning needs to take account of individual needs assessments and needs to facilitate seamless service provision for families.

Commissioning needs to influence other systems to ensure that families receive the right care at the right time and in the right place. One concrete example of this is that IT systems need to be able to talk to each other so that information can be shared quickly and easily across services.

**Q.4 Taking account of the context and content of this document, are there any other important issues not addressed? YES**

Not all of the needs which children with life-threatening and life-limiting conditions have are palliative - many are common with children with less complex disabilities. It is therefore important that children who need palliative care have access to the range of services available for disabled children in Northern Ireland - and that these services are integrated and centred on children and families.

Greater emphasis needs to be put on mitigating the financial impacts on families of caring for a child with complex healthcare and palliative care needs. Significant costs are incurred by families in meeting their child's needs. Families may need to accommodate carers in their house 24 hours a day, seven days a week. Heating and electricity bills are often greater due to the costs of running and charging specialist mattresses, ventilators, chairs and suction machines.

Many parents of ventilator or technology-dependent babies and children under the age of three are unable to transport them home from hospital because their family car cannot bear the weight of their child's equipment. Many do not have access to (and cannot afford) the broad-based vehicles which are needed. This issue is exacerbated by the fact that only children over the age of three can access the mobility component of the Disability Living Allowance (DLA). This is the case in Northern Ireland, as it is in other parts of the UK.

Overall, we believe that there should be a gradual reduction - rather than a sudden end - to benefits paid to families who have cared for a child who has died

Access to 24/7 specialist advice and information for professionals in the community is a clearly identified need. NICH currently provides this for families who use hospice services, and the professionals working with them. This needs to be available more widely and in a planned and systematic way.

In addition bereaved parents raised the issue that, while there is a process in place to apply for assistance with funeral expenses when an adult dies, there is no such assistance for a child. We believe that families with low incomes should be supported in meeting funeral costs when a child dies and should be exempt from paying death certification charges

Together for Short Lives believes that every employer in Northern Ireland should have a bereavement policy which includes an entitlement to time off for bereaved family members and agreed arrangements for pay during this period. This should be supported by a statutory bereavement payment for those who are self-employed or employed on zero-hours contracts.

We believe that family carers who have provided long-term, full-time care to a child who has died are offered training and support to return to work.

Parents have commented to NICH that while the recommendations in the review are welcome and wide ranging they seem to be very medical in their focus. They identified their significant needs at different times in their child's journey for emotional and/or psychological support. They recommended a co-ordinated, structured approach to providing for the emotional needs of parents on the basis that they are responsible 24 hours a day for the care of their children and need to be emotionally well enough to do so over a sustained period of time. Many children with palliative care needs need support over years rather than months and NICH recognises the need for planned, meaningful and sustained family support throughout the child's life and into the bereavement period.

In each of NICH's focus groups, parents told NICH that, first and foremost, they need to be their child's mummy or daddy, not their carer. They say they need professionals to understand that their focus needs to be on being the best parents they can be for their child. It's not in anyone's best interests if all their time and energy goes on managing the system and fighting to get the care their needs.

**Please use space below to address any issues not asked in above questions.**

**Equality implications**

Q5. Do you think the proposals are likely to have an adverse impact on any of the nine equality groups identified under Section 75 of the Northern Ireland Act 1998? If yes, please state the group or groups and provide comment on how these adverse impacts could be reduced or alleviated in the proposals

Yes  No

Response:

Q6. Are you aware of any evidence, qualitative or quantitative, that the proposals may have an adverse impact on equality of opportunity or on good relations? If yes, please give details and comment on what you think should be added or removed to alleviate the adverse impact.

Yes  No

Response:

Q7. Could the proposals better promote equality of opportunity or good relations? If yes, please give details as to how.

Yes  No

Response:

Families tell NICH that services are inconsistent and vary between local areas. A new regional strategy and appropriate resourcing could help give all families equal access to services.



THANK YOU FOR YOUR COMMENTS.

### FREEDOM OF INFORMATION ACT 2000 – CONFIDENTIALITY OF CONSULTATIONS

The Department will publish a summary of responses following completion of the consultation process. Your response, and all other responses to the consultation, may be disclosed on request. The Department can only refuse to disclose information in exceptional circumstances. **Before** you submit your response, please read the paragraphs below on the confidentiality of consultations and they will give you guidance on the legal position about any information given by you in response to this consultation.

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