

**SERVICE FRAMEWORK**

**CHILDREN AND YOUNG PEOPLE**

**Consultation Response Questionnaire**

*November 2014*

## CONSULTATION RESPONSE QUESTIONNAIRE

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:

E-mail: [serviceframeworks@dhsspsni.gov.uk](mailto:serviceframeworks@dhsspsni.gov.uk)

Written: Service Frameworks Unit  
DHSSPS  
Room D1  
Castle Buildings  
Stormont Estate  
Belfast, BT4 3SQ

Tel: (028) 9052 3920

Fax: (028) 9052 2500

**Responses must be received no later than 30<sup>th</sup> January 2015.**

I am responding: as an individual  
on behalf of an organisation  
(please tick a box)

  

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Organisation: **Together for Short Lives**

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## Service Framework for Children and Young People – Consultation Response Questionnaire

### Background

The overall aim of the Department of Health Social Services and Public Safety (DHSSPS) is to improve the health and social well being of the people of Northern Ireland. In achieving this, the DHSSPS has been developing a range of Service Frameworks which set out explicit standards for health and social care that are evidence based and are capable of being measured. Through the setting of targets, timeframes and measurable outcomes, they have the capacity to achieve and demonstrate quality improvement.

The Service Framework for Children and Young People sets standards that relate to: improving birth outcomes; promoting child development across the life course; children and young people with acute and long term conditions; childhood disability; positive mental health; and children and young people in special circumstances.

Each standard is supported by levels of performance to be achieved over the Framework's three year life cycle, after which it will be subject to both review and refinement in the light of new evidence. This ensures that there is a solid basis for continued improvement in the quality of health and social services.

### Purpose

This questionnaire seeks your views on the Service Framework for Children and Young People, and should be read in conjunction with the document which includes the draft standards. It is particularly important to know whether the proposed standards will ensure that health and social care services are safe, effective and person-centred.

All Service Frameworks incorporate a specific set of standards that are identified as generic. The generic standards were subject to public consultation during 2012, with the consultation closing on 6 August 2012. The standards have since been finalised and agreed.

We are therefore not seeking comment on these standards as part of this consultation. The relevant standards are clearly marked as generic throughout the document.

### The consultation questionnaire

The questionnaire can be completed by an individual health professional, stakeholder or member of the public, or it can be completed on behalf of a group or organisation.

**Part A:** provides an opportunity to provide some general feedback on the service framework document and should be completed by all respondents.

**Part B:** provides an opportunity for respondents to give additional feedback relating to specific standards and/or sections of the service framework.

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Please indicate which section(s) you are providing feedback on:

- I am providing general feedback on the document and will complete Part A.
- I am providing general feedback on the document with a focus on the specific section(s) indicated in the table below and will complete Part A and Part B.

Please tick which sections or subsections you are providing feedback on	
Summary of Standards	
Section 1: Introduction	
Section 2: Service Framework for Children and Young People	
Section 4: Standards: Improving Birth Outcomes	
Section 5: Standards: Promoting Child Development Across the Life Course	<b>Yes</b>
Section 6: Standards: Children and Young People With Acute and Long Term Conditions	<b>Yes</b>
Section 7: Standards: Childhood Disability	
Section 8: Standards: Positive Mental Health and Emotional Wellbeing of Children and Young People	
Section 9: Standards: Children in Special Circumstances	

**Part A – General feedback on the document (all respondents please complete this part).**

**Q1.** Please indicate your views on the following statement (please circle response)

“In general the language and organisation of the document is easy to follow.”

Strongly agree      **Agree**      Neither      Disagree      Strongly disagree

Comments:

**Q2.** Please indicate your views on the following statement (please circle response)

“The standards covered by the service framework are important for children and young people”.

**Strongly agree**      Agree      Neither      Disagree      Strongly disagree

Comments:

Together for Short Lives welcomes the standards focus on children’s palliative care. We are grateful to DHSSP for recognising the distinct nature of children’s palliative care compared to the palliative care needed by adults.

We also welcome the focus on respite, multi-agency working, personalised planning approaches and on the importance of clinical networks. We ask that the terminology of ‘respite’ is changed to ‘short break’. This would better reflect the social model of disability which we advocate (an example of this perspective is set out at <https://www.mencap.org.uk/blog/why-short-breaks-and-not-respite>).

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**Q3.** Please indicate your views on the following statement (please circle response)

“Overall this framework will provide an opportunity to help set priorities for commissioning services for children and young people”.

Strongly agree

**Agree**

Neither

Disagree

Strongly disagree

Comments:

**Q4.** Which of these standards will have the greatest impact on the health and wellbeing of children and young people, and why?

Comments:

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**Q5.** Which of these standards might affect existing or potential health inequalities for people in Northern Ireland, and how? Please consider social, economic and geographic challenges in response to this question.

Comments:

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**Equality implications**

Before completing this section, please refer to Appendix 2 which relates to equality of opportunity, and the guidance regarding this produced by the Equality Commission for Northern Ireland.

**Q6.** What is the likely impact on equality of opportunity for those affected by this policy, for each of the Section 75 equality categories?

Minor       Major       None

If you have indicated minor or major, please provide details:

**Q7.** Are there opportunities to better promote equality of opportunity for people within the Section 75 equalities categories?

Yes       No

Comments:

Section 75 obliges public authorities to have due regard to the need to promote equality of opportunity between people with a disability and people without. We believe that the framework provides an opportunity to reduce inequality between disabled and non-disabled children and young people.



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**Q8.** To what extent is the policy likely to impact on good relations between people of different religious belief, political opinion or racial group?

Minor       Major       None

If you have indicated minor or major, please provide details:

Comments:

**Q9.** Are there opportunities to better promote good relations between people of different religious belief, political opinion or racial group?

Yes       No

Comments:

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**Q10.** Please use the box below to insert any further comments, recommendations or suggestions you would like to make in relation to the draft Service Framework for Children and Young People.

Comments:

We ask that the framework complements the forthcoming Northern Ireland children's palliative care strategy and implementation plan. This was referenced by DHSSPS in its report of the review of children's palliative and end of life care in Northern Ireland published in January 2014.

**Please continue and complete Part B, or return your response questionnaire.  
Responses must be received no later than <Insert date>  
Thank you for your comments.**

**Part B – Feedback relating to specific standards and/or sections of the service framework.**

If necessary please copy and complete this part of the questionnaire for each section or standard you are reviewing.

*Please insert the specific section or standard you are reviewing in the box provided*

**Promoting Child Development Across the Life Course  
Standard 12**

In this standard, we ask that children with life-limiting and life-threatening conditions are included as a specific group which should receive early intervention services. Intervening early in the lives of children who need palliative care can help to prevent or manage emerging problems - and improve outcomes. Where children's lives are severely limited, getting the right support in time is particularly important for families.

**Children and Young People with Acute and Long term Conditions  
Standard 17**

We welcome standard 17. However, we question why the database cited in the key performance indicators should be restricted to technology-dependent children. We ask DHSSPS to consider extending this to all young people with life-limiting conditions aged 13 – 25 - all of whom should have access to age-appropriate services.

As further indicators, we suggest that trusts:

- set up and maintain a transition group with an executive lead and key stakeholders which include young people
- track transition assessments.

**Children and Young People with Acute and Long term Conditions  
Standard 18**

We suggest that further key performance indicators could include:

- having an organisational transition policy, pathway and operational guide in place; this would be jointly developed by those providing care to children, young people and adults, as well as young people themselves
- having an operational transition plan by clinical speciality which includes condition-specific elements of transition
- access to peer support

- identifying relevant training available on caring for young people
- having a patient survey on the transition experience.

### **Children and Young People with Acute and Long term Conditions Standard 23**

We welcome standard 23 which states that children who need palliative care and their families should be supported to enable them to live at home and participate in family, school and community life. In the key performance indicator column, we ask that DHSSPS is careful to ensure consistent terminology on emergency care plans. In the draft, the term 'emergency healthcare plans' is also used: while this is inconsistent, the latter term also implies that advance or emergency planning only needs to involve health services. We believe that advance or emergency planning should include all the agencies involved in caring for a child and their family.

On this basis, we think that the agencies referenced in performance indicator one should also include social care teams, education settings and any other professionals who are caring for the child. Care need to may be provided in a child's school, for example; where this is the case, the school should be involved in planning and agreeing how this care should be provided.

Other indicators could include:

- Families receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and are be treated with respect, honesty and sensitivity.
- Information is provided for the child and the family in a form that they can understand.
- Every child and family diagnosed in the hospital setting has an agreed transfer plan involving hospital, community services and the family, and is be provided with the resources they require before leaving hospital.
- Every family receives a child and family centred multi-disciplinary and multi-agency assessment of their needs as soon as possible after diagnosis or recognition, and has their needs reviewed at appropriate intervals.
- Every child and family has a multidisciplinary, multi-agency care plan, developed in partnership with them for the delivery of co-ordinated care to enhance family strengths and meet need.
- A multi-disciplinary and multiagency team is identified in agreement with the family and using key working principles. Wherever possible this involves all agencies involved in supporting the child and family, including the child's community nursing team, allied health professionals, hospice, local acute and tertiary hospital services, education, social care and short break services.

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- Every child and family is helped to decide on an end of life plan and is provided with care and support to achieve this.
- Bereavement support is provided along the care pathway and continues throughout the child's death and beyond.

**Q(i).** Please indicate your views on the following statement (please circle response)

"It was easy to locate my specific standard/section of interest in the service framework document."

Strongly agree

**Agree**

Neither

Disagree

Strongly disagree

Comments:

**Q(ii).** Service frameworks are viewed as active documents which evolve over time to include new scientific evidence for improving care. Are you aware of any key evidence or other information which is missing, which should be included and which would alter the nature of this particular section/ standard?

Yes

No

Comments:

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**Q(iii).** Please indicate your views on the following statement (please circle response)

“The performance indicators and the expected performance levels where provided, are reasonable and they will help progress towards achieving the overarching standard(s).”

Strongly agree      **Agree**      Neither      Disagree      Strongly disagree

Comments:

**Q(iv).** Please indicate your views on the following statement (please circle response)

“I plan to use the/these standard(s) to improve my practice, or services for ‘children and young people.’

Strongly agree      Agree      Neither      Disagree      Strongly disagree

Comments:

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**Q(v).** Please use the box below to insert any further comments, recommendations or suggestions you would like in relation to this particular standard or section.

Comments:

**Please return your response questionnaire.  
Responses must be received no later than 30<sup>th</sup> January 2015. Thank you for your  
comments.**



*Appendix 1*

*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.

The Freedom of Information Act gives the public a right of access to any information held by a public authority, namely, the Department in this case. This right of access to information includes information provided in response to a consultation. The Department cannot automatically consider as confidential information supplied to it in response to a consultation. However, it does have the responsibility to decide whether any information provided by you in response to this consultation, including information about your identity should be made public or be treated as confidential.

This means that information provided by you in response to the consultation is unlikely to be treated as confidential, except in very particular circumstances. The Lord Chancellor's Code of Practice on the Freedom of Information Act provides that:

- the Department should only accept information from third parties in confidence if it is necessary to obtain that information in connection with the exercise of any of the Department's functions and it would not otherwise be provided
- the Department should not agree to hold information received from third parties "in confidence" which is not confidential in nature
- acceptance by the Department of confidentiality provisions must be for good reasons, capable of being justified to the Information Commissioner

## Service Framework for Children and Young People – Consultation Response Questionnaire

For further information about confidentiality of responses please contact the Information Commissioner's Office (or see web site at: <http://www.informationcommissioner.gov.uk/>). For further information about this particular consultation please contact Anne-Marie Blaney (contact details are shown on page 2).

*Appendix 2*

Section 75 of the Northern Ireland Act 1998 requires the Department to “have due regard” to the need to promote equality of opportunity between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation; between men and women generally; between persons with a disability and persons without; and between persons with dependants and persons without. The Department is also required to “have regard” to the desirability of promoting good relations between persons of a different religious belief, political opinion or racial group.

In keeping with the above statutory obligations and in accordance with guidance produced by the Equality Commission for Northern Ireland, the Department has carried out a preliminary equality screening exercise to determine if the standards proposed in the Service Framework for Children and Young People, are likely to have a significant impact on equality of opportunity and should therefore be subject to an Equality Impact Assessment (EQIA). The Department has concluded that an EQIA is not required. This decision will be reviewed following the completion of the public consultation.

Produced by:  
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