

## Summary: Intervention & Options

<b>Department /Agency:</b>	<b>Title:</b> <b>Impact Assessment of a National Framework for Assessing Children's Continuing Care Needs</b>	
<b>Stage:</b> Consultation	<b>Version:</b> v1	<b>Date:</b> 29 September 2008
<b>Related Publications:</b> none		

### Available to view or download at:

<http://www.dh.gov.uk/en/Consultations/index.htm>

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### What is the problem under consideration? Why is government intervention necessary?

An objective of healthcare policy is to provide care closer to patients' homes. The consultation on Guidance on provision of continuing care to adults, published by DH in 2006, acknowledged the needs of children are different and advised a separate paper would be developed. Since this time Ministers have committed to developing a Framework for Children.

Due to an absence of guidance a multiplicity of systems exist resulting in inconsistency of needs assessment and lack of transparency in the allocation of resources. Developing guidance will also promote objectivity in decision-making.

### What are the policy objectives and the intended effects?

The aim is to assist PCTs and LAs to develop consistent joint decision-making processes for the provision of continuing care for children in a transparent, fair and equitable manner according to need.

The intended effect of this guidance is to promote a more objective approach to the provision of continuing care in which families and professionals have greater confidence and satisfaction that the needs of the child and family will be assessed and individual decisions based on a common assessment of need. Future development of services will be better informed by consistent data.

### What policy options have been considered? Please justify any preferred option.

The top three options considered-

1. Do nothing - continue with the current lack of a systematic approach. This was rejected by professionals and service user stakeholders when consulted about this.
2. Use the Adult Continuing Care Guidance - also rejected by stakeholders as it reflects neither the family centred approach and the education needs of children nor the legal drivers for children.
3. Develop specific guidance tailored to the needs of children, young people and their families - this is stakeholders' preferred option.

### When will the policy be reviewed to establish the actual costs and benefits and the achievement of the desired effects?

The effects of the guidance will be reviewed by December 2012.

### **Ministerial Sign-off** For consultation stage Impact Assessments:

*I have read the Impact Assessment and I am satisfied that, given the available evidence, it represents a reasonable view of the likely costs, benefits and impact of the leading options.*



## Summary: Analysis & Evidence

<b>Policy Option:</b>	<b>Description:</b>
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<b>COSTS</b>	<b>ANNUAL COSTS</b>	Description and scale of <b>key monetised costs</b> by 'main affected groups' Costs of training managers and practitioners in the use of the Framework and Decision Support Tool, cost of training staff in role of key worker, cost of admin staff, IT costs			
	<b>One-off</b> (Transition) <b>Yrs</b>		1		
	<b>£ 2.22m</b>				
	<b>Average Annual Cost</b> (excluding one-off)				
	<b>£</b>		<b>Total Cost (PV)</b>	<b>£ 2.22m</b>	
Other <b>key non-monetised costs</b> by 'main affected groups'					

<b>BENEFITS</b>	<b>ANNUAL BENEFITS</b>	Description and scale of <b>key monetised benefits</b> by 'main affected groups'			
	<b>One-off</b> <b>Yrs</b>				
	<b>£</b>				
	<b>Average Annual Benefit</b> (excluding one-off)				
	<b>£</b>		<b>Total Benefit (PV)</b>	<b>£</b>	
Other <b>key non-monetised benefits</b> by 'main affected groups'					
Key benefits are: fairness and equity in needs assessment across PCTs; assessed needs are better met.					

**Key Assumptions/Sensitivities/Risks** Assumption: existing resources will be allocated more equitably  
 Risks: More transparency in process may produce more challenges to decisions;  
 Consistency of process across PCTs may mean wider range of children are referred for assessment

Price Base Year	Time Period Years	<b>Net Benefit Range (NPV)</b> £	<b>NET BENEFIT (NPV Best estimate)</b> £
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What is the geographic coverage of the policy/option?	England			
On what date will the policy be implemented?	to be determined			
Which organisation(s) will enforce the policy?	PCTs			
What is the total annual cost of enforcement for these organisations?	£			
Does enforcement comply with Hampton principles?	Yes/No			
Will implementation go beyond minimum EU requirements?	No			
What is the value of the proposed offsetting measure per year?	£			
What is the value of changes in greenhouse gas emissions?	£			
Will the proposal have a significant impact on competition?	Yes/No			
Annual cost (£-£) per organisation (excluding one-off)	Micro	Small	Medium	Large
Are any of these organisations exempt?	Yes/No	Yes/No	N/A	N/A

<b>Impact on Admin Burdens Baseline</b> (2005 Prices)			(Increase - Decrease)
Increase of    £	Decrease of    £	<b>Net Impact</b>	£

Key:    Annual costs and benefits: Constant Prices    (Net) Present Value

## Evidence Base (for summary sheets)

[Use this space (with a recommended maximum of 30 pages) to set out the evidence, analysis and detailed narrative from which you have generated your policy options or proposal. Ensure that the information is organised in such a way as to explain clearly the summary information on the preceding pages of this form.]

### What is Children's Continuing Care?

*Children's Continuing Care* is a general term that describes a tailor made package of care needed over an extended period of time for children with complex health needs which arise because of disability, accident or illness (including life limiting or life threatening conditions). This is for children and young people whose health needs cannot be met by existing local health services. The aim of the package is to support the child/young person's parents or carers to manage their child/young person's care at home and/or in other settings. It may require services from the NHS and/or Local Authority services to enable the person to function in the community.

Improvements in health care have improved the life expectancy of children and young people who have complex long term, life-threatening or life-limiting conditions. However many of these children require on-going continuing health care. It is widely accepted that the best place to care for children especially if they have complex continuing healthcare needs is in their own homes, with their families and with proper support, and that children and families should be closely involved in decisions regarding future care needs.

This document relates to children and young people 0-18 who may have continuing care needs. Children's Continuing Care differs from adult NHS Continuing Healthcare and NHS funded Nursing Care which applies to anyone 18+ who needs to be considered for a health funded package of care that will be arranged and funded solely by the NHS. By contrast, Children's Continuing Care is family centred and involves health, social care and education components. It is a framework for assessment, decision making and provision of a jointly arranged and funded package of care needed over an extended period of time for children with complex healthcare needs which arise because of disability, accident or illness.

### The Case for Action/ Government Intervention

Since the publication of the *National Service Framework for Children, Young People and Maternity Services* (the NSF) in 2004 a number of good practice guides and tools have been developed to support implementation, including support to improve provision for children and young people with continuing care needs. When the National Framework for assessing NHS Continuing Healthcare and NHS funded Nursing care in England' ie the Adult Framework was issued for consultation in 2006 it acknowledged the needs of children and young people are different and promised a separate paper on children and young people's continuing healthcare based on similar principles and values. There was further government commitment with the publication of the White Paper *Our health, our care, our say* in January 2007 in which there was a pledge to 'clarify how the NHS Continuing Care strategy should work for children'. The White Paper also said, "for disabled children, children with complex health needs and those in need of palliative care, PCTs should ensure that the right model of service is developed by undertaking a review of capacity (including children's community nursing) and delivery of integrated care pathways against National Service Framework standards, agreeing service models, funding and commissioning arrangements with their SHAs". Since this time Ministers have committed to developing a Framework for children.

This best practice guidance on children's continuing care responds to commitments made on the publication of the NSF and the White Paper that continuing care for children and young people would be given further consideration. In addition it will support the implementation of

NSF Standard 3 which expects “children, young people and their families will receive high quality services which are co-ordinated around individual needs and take account of their views”. It will also support the implementation of NSF Standard 8 “Children and young people who are disabled or who have complex health needs, receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, enable them and their families to live ordinary lives”.

The guidance also reflects the approach set out in *Aiming high for disabled children: better support for families (AHDC)* a joint HMT/DFES report published in May 2007 on services for disabled children (including those with complex health or palliative care needs). The Report identified three priority areas to improve outcomes for disabled children:

- Access and empowerment
- Responsive services and timely support; and
- Improving quality and capacity

To empower disabled children, young people and their parents, the Government has set out a clear standard - a core offer, and given disabled children and their families the option to be fully involved in local service development and in designing their packages of care. The national core offer is a statement of the standards which families with disabled children can expect across the country from local services. It encompasses information and transparency, assessment, participation and feedback.

Application of the National Framework will contribute to how PCTs, with their LA partners, meet the Core Offer commitment locally and will enable children and young people, parents and carers to understand the basis on which decisions are made.

The Government expects LAs, PCTs and schools to engage parents of disabled children (including those with complex health needs) in the design and delivery of services. Understanding the basis on which their child’s needs have been assessed will empower parents so that if necessary not only can they challenge the PCT decision on which services to fund in respect of their own child but this will inform their participation in the design and delivery of future services.

The case for action is strongly supported by a range of stakeholders, including families. Evidence from parents and health professionals, at a stakeholder event convened in March 2006; evidence presented to an Independent Review of Children’s Palliative Care; and evidence presented to the joint HMT/[ the then] DfES Review of Services for disabled children in 2006/2007 which culminated in AHDC; all emphasised the lack of consistency and transparency in decisions made regarding the provision of care. More recently at recent regional events to launch Better Care: Better Lives, parents of children and young people with palliative care needs, have frequently described the degree of care they have received as down to luck and the strength of argument put forward by themselves and healthcare professionals, illustrating how subjective the existing arrangements have been.

Finally, disabled children (including those with complex health needs) are identified as a local priority in the NHS National Operating Framework for 2008-11. PCTs, in consultation with their local partners, are encouraged to identify actions and set local targets for improving the experience of, and range of services for, children with disabilities and complex health needs and their families. This too will mean that PCTs will need to take steps to identify the number of children and young people needing services and to assess their needs.

## The Proposed National Framework

At present PCTs, either alone, or with LA partner agencies, use a mixture of their own tools and those also used by other agencies such as the Common Assessment Framework (CAF) and core assessments, and adopt their own method of deciding which children or young people have continuing care needs. Families report that they do not always know whether they have had their needs assessed for a continuing care package and report long delays in decision making. This can mean there is no transparency in when, or how assessments are carried out, the timeliness of those assessments or how decisions are made and leads to wide variations across England.

The National Framework provides for the first time, a tool to assist PCTs, working with LAs, to identify children and young people (under 18years) who have a continuing care need and to assess the level of need. It comprises of best practice guidance which includes-

- A set of key principles, core values and best practice for considering continuing care needs
- a Decision Support Tool ( DST) for use by health practitioners assessing whether a child or young person has a continuing care need. The DST sets out a series of Domains intended to ensure that the assessor gets a rounded picture of the child or young person's health needs
- a continuing care pathway, drafted by the Association of Children's Palliative Care and based on their widely accepted model Care Pathway for children and young people with a life limiting or life threatening condition
- A summary of the Haringey judgement- a 2005 court case which clarifies the boundaries between health and social care provision. The particular case concerned whether a LA or PCT should be responsible for providing certain types of nursing respite care. The Judge concluded that the nursing service was not of a type which should be provided by a LA under the Children Act and the PCT should provide it under the NHS Act.

The National Framework will assist PCTs and LAs to obtain a complete picture of the child's health needs in order to make a decision about whether to fund a continuing care package. When the National Framework is operational, PCTs/LAs should determine a child or young person's need for continuing care by reference to the assessment process set out in the DST in the National Framework. This will ensure that all decisions are based on *need* and all assessments are made against the same criteria.

It is intended that the proposed National Framework will enable children/young people and their families to receive timely family centred assessments, decisions and appropriate packages of care. The aim is that this will facilitate early discharge from hospital, support care at home, or as close to home as possible, and reduce the need for residential placements. The care pathway that supports the framework will enable local PCTs/LAs to establish robust processes that are responsive, proactive and continually reviewed.

In addition to benefiting the care of existing children who have continuing care needs, adherence to the National Framework for Assessing Children's Continuing Care guidance will enable authorities to assemble more consistent data on need and to use this to plan future service developments in a more systematic manner.

We anticipate that the guidance will be of further benefit by helping to speed the discharge planning process for children who currently rely on hospitals for a considerable amount of their care. There have been instances where children have been inappropriately admitted to hospital when they might have been cared for at home with proper support or alternatively where discharge has been unacceptably delayed while awaiting assessment for continuing care.

Overall, we believe that use of a National Framework will lead to more efficient and equitable decisions being made. Better reporting of families' needs will also enable decision makers to make quicker decisions about the care they can fund. This in turn should enable more cases to be considered for continuing care and, in the case of children and young people waiting to be discharged from hospital, may therefore reduce the time that they have to wait.

The National Framework recommends that decisions are notified to the referrer within 5 working days and the decision as to which service can be provided should be notified within 28 days. Knowing they have had their continuing care needs assessed and knowing when they will receive the decision will help to relieve the stress on families.

Although the National Framework itself is a best practice guide, we will consider the status of the Decision Support Tool (DST) and whether the Secretary of State should direct PCTs and LAs to apply it when making their assessment. Even if use of the DST is made mandatory, whether to fund an assessed need for continuing care would remain for local determination.

### **Assessing the impact of the National Framework: Number of children in need of continuing care**

It is hard to find a consistent definition of children with continuing care needs: the following definitions have been used by a selection of Primary Care Trusts (PCTs) or trusts:

- children with multiple disabilities and complex health needs
- children with life-limiting and/or life-threatening illness, or suffering from a chronic illness or disease, children with physical and/or learning disability and/or sensory impairment and/or severe communication disorders, children with emotional behavioural and mental health needs including children with challenging behaviour and those at risk of harming themselves and/or others
- children with complex health care needs that require intervention where mainstream services do not meet their needs
- children that need care over an extended period of time who have complex care needs which arise because of disability, accident or illness

It is clear that in some PCTs continuing care assessments are restricted to children with complex 'physical medical' care need, often a combination of technology dependence and life-limiting/life-threatening illness. In other parts of the country a wider approach has allowed for the inclusion of children with learning disabilities, mental ill-health and autism spectrum disorder.

It is therefore very difficult to say how many children (0-18) have continuing care needs nationally as defined by the new framework. However, various studies indicate the following estimates:

- 15,000 – 30,000 children with multiple disabilities and complex health needs (AC Ross, Chief Executive, Tadworth Children's Trust) <sup>1</sup>
- 15,000-19,000 children with life-limiting or life-threatening conditions (including muscular dystrophy, technology dependent, cancer, cystic fibrosis and other complex health needs) (York Health Economics Consortium) <sup>2</sup>
- Estimates from the evaluation of the National Assessment Framework pilot study suggest that between 5,000 and 6,000 cases are assessed for children's continuing care each year, or around 470 per month. The average number of assessments per PCT per year

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<sup>1</sup> [http://www.hm-treasury.gov.uk/media/0/B/cypreview2006\\_childrenstrust2.pdf](http://www.hm-treasury.gov.uk/media/0/B/cypreview2006_childrenstrust2.pdf)

<sup>2</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_074459](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074459)

is around 40, but the number varies considerably by PCT. More than half (55%) are new cases. An estimated 4,000 children in England are currently in receipt of continuing care at any one time.

This implies that more than half of the children who potentially have continuing care needs are neither seen for the first time nor reviewed in a given year. Suggested reasons for this difference are:

- Some of the 15,000 or so children with complex care needs may include those whose parents want to look after their children themselves for various reasons such as when children are near the end of their lives.
- Some of the cases referred for continuing care have needs met by existing universal and specialist services. This varies considerably between PCTs.
- There are a few hundred children in hospital waiting to be assessed including some in neonatal services and some who are technology dependent.<sup>3</sup>
- As explained above, there has been an inconsistent approach to provision for children with mental ill-health, learning disabilities and autism spectrum disorders, and these groups cover a wide spectrum of needs some of whom will not have continuing care needs .

There is some evidence that the number of children with continuing care needs is increasing, partly because of technological advances and improved treatments meaning that:

- More very pre-term babies survive into childhood – the Confidential Enquiry into Stillbirths and Deaths in Infancy<sup>4</sup> found that 88% of babies born at 27 to 28+ weeks gestation survived to at least 28 days, double the rate observed 15 years ago. However the children who survive are no less disabled – for example the incidence of cerebral palsy in pre-term infants was found to remain static in a review of 17 birth weight studies published between 1988 and 2001.<sup>5</sup>
- More children survive traumatic accidents with multiple impairments for example road accidents
- More children survive into adulthood with what used to be considered diseases of childhood like muscular dystrophy, cystic fibrosis.

A study of death rates for children aged 0-19 in the East of England by the Eastern Region Health Observatory shows that they came down from around 28 per 100,000 in 2001 to 24 in 2005. Similar trends were seen in the rate of death due to conditions likely to require palliative care. The same study found that the trend in 5-year survival among children diagnosed with malignant cancer in the East of England was up from 55% survival in 1989 to 73% in 2001.

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<sup>3</sup> Consultant Nurse, Children with Complex Health Needs

<sup>4</sup> <http://www.cemach.org.uk/Publications/CEMACH-Publications/CESDI-Publications.aspx>

<sup>5</sup> Patterns of motor disability in very preterm children. Mental retardation and developmental disabilities Research Reviews 2002; 8 (4): 241-8.

On the other hand, a report from one of the PCTs involved in the pilot study says that “numbers are not rising significantly year-on-year”.

Given the limited information available and the uncertainties described, we have based our assumptions on 5,000-6,000 children and young people being assessed each year, drawing on the evaluation of the National Framework pilot study. .

## **Assessing the impact of the National Framework : Analysis of Costs and Benefits**

### **Option 1**

**Do nothing** : allow PCTs to continue to develop their own systems for making decisions about the provision of continuing care. This will mean that the current inequity of provision and lack of transparency in which decisions are made will continue and the existing lack of information on the number of children in receipt of continuing care and the associated costs will continue. This approach also fails to address the government commitment that such guidance would be forthcoming. It also fails to recognise that a National Framework will make a significant contribution to the delivery of the AHDC Core Offer locally and its absence would have a negative impact on the other commitments set out in AHDC.

**Benefits:** this option represents ‘no change’ therefore it exacerbates existing problems so the net benefit is zero

### **Option 2**

**Use the Adult Framework:** there was consensus amongst PCT, LA and service user stakeholders, at the event held in 2006 and subsequently, that this option would not reflect the family centred approach needed. That approach is essential because families provide the majority of care to disabled children at home. It is also necessary for health, social care and education components to be incorporated and the adult Framework does not reflect the different legal drivers eg. the Children Act and the requirements on the NHS which apply to children’s care. It was not thought that PCTs would be able to respond to these requirements simply by applying the Adult Framework.

**Costs and Benefits:** The Adult Framework is not considered to be fit for purpose. Application of the adult framework would cost the same as the preferred option 3 to implement but as it does not reflect the different legal drivers which apply to children and young people or the family centred approach and the education needs of children it would deliver significantly less benefit and should therefore not be used.

### **Option 3**

Develop specific guidance tailored to the needs of children and young people and adapt the Adult Decision Support Tool. This will allow consistent and comprehensive assessments and decision-making focussed on the needs of this group of individuals taking into account their specific needs and using a framework that recognises the different legislative drivers. Aligning the children’s framework as closely as possible with the adult one, allowing for three different factors, will assist when young people move from paediatric care to adult care. From the stakeholder event we know that service users would prefer a Framework designed specifically for children and young people to achieve the best outcomes for their children.

We have already tested the usefulness of an earlier version of the National Framework for Assessing Children’s Continuing Care with 12 PCTS in a pilot study and have evaluated their findings. Overall, experience of users was that the DST was found to add value to their decision making and assessment process. Some changes were recommended and have been incorporated into the version being consulted on. Best practice guidance was also recommended to include quality holistic assessments and linkages with other processes and

pathways. This too has been addressed in the Framework document. This is our preferred option.

**Benefits:** The guidance proposes to improve outcomes for children who have complex continuing care needs and their families by developing a comprehensive continuing care assessment framework thus assuring families their needs are being considered in a transparent, consistent and equitable manner.

In addition it aims to assist PCTs and LAs to make objective decisions about the support required by individual children and their families given that there are relatively small numbers of children requiring continuing care. This is particularly important when it is predicted that the numbers of these children will rise in future years and the subsequent resource implications.

**Costs:** The analysis of costs and benefits has been split into 2 parts:

1. Those relating to the introduction and administration of the new framework
2. Those flowing from decisions taken locally by PCTs on the basis of assessments carried out using the new framework. These will be dependent on local decision-making, as the introduction of the framework itself is intended to be cost neutral, supporting greater consistency and efficiency in decision-making.

### 1. Costs and benefits of administering the framework

Anticipated costs are: (see table in annexes)

- Training in the use of the framework and the DST, including time during which trainees are away from normal duties
- Management briefings to give an overview of the new framework in the workplace
- Practitioner training sessions on using the DST for nurses, doctors, social workers, occupational therapists, physiotherapists and anyone involved in assessment
- Additional administrative staff to service assessment and decision-making panels
- Cost of shared electronic systems

Not included in admin costs:

- Costs of setting up assessment panels, with multi-agency working, formal review process, as these should already be in place.
- Extra time for all decision makers and assessors to adopt improved procedures. We expect use of the DST to improve information to the panels thus reducing the time spent in multi-agency meetings
- Training staff in the role of the key worker (existing policy).

These administration costs are set out in the summary sheet at page 2. Costs of services consequent on continuing care assessment are not included as the Government will not be specifying eligibility criteria: PCTs and LAs remain responsible for determining local service provision and priorities to meet the needs of their local population. This means that after an assessment of the child or young person's continuing care need PCTs and LAs will need to consider what care package to fund.

The framework will ensure that all families' needs are assessed in a transparent consistent and equitable manner.

### 2. Further possible costs and benefits relating to changes in care requirements

- numbers quoted in the evidence base suggest not all eligible children are being assessed. If there are eligible children in hospital or being cared for at home without help, the increased visibility and efficiency of the new framework might see more children being referred. If use of the DST is mandatory, some of these children may be assessed as having a need for continuing care. An increase of

1% in the number of children currently being awarded a continuing care package would result in increased costs of around £750,000 to £900,000, based on average cost per child of £15,000 per year (Unit Costs of Health and Social Care 2007<sup>6</sup>). However the pilot evaluation report showed that the framework resulted in some cases being assessed as having less need of care than under existing systems. It still remains for the PCT to decide what to fund.

- There could be a financial benefit to the NHS of supporting the move of a child out of hospital and into the home –York Health Economics Consortium’s review of palliative care services (2007) for DH<sup>7</sup> estimates cost savings of around £4,000 per year for a technology dependent child; around £1,000 per year for a child with complex needs including cardiac problems and muscular dystrophy. A 2003 report by Dr. Barnardo’s Policy and Research Unit<sup>8</sup> estimates that the annual cost of home ventilation (1998 costing) for a child receiving 24-hour care was £160,000 - £180,000, while a bed in Great Ormond Street Hospital’s Transitional Care Unit was £258,420 and beds in Paediatric Intensive Care Units ranged between £438,000 - £657,000 per year depending on location.
- There could be benefits through reducing social admissions to hospital or residential nursing homes for short breaks if more care is provided in the home.
- It is not known whether the new framework will result in more or fewer challenges to decisions. The pilot evaluation suggested that some pilot PCTs which saw the fewest challenges were already using assessment methods similar to the new framework, and that challenges occurred where families had unrealistic expectations due to non-transparent systems.

The consultation will be used to help inform these questions.

### **Other Options considered**

Adapt the adult Framework: although the adult Framework could be adapted to address the wide range of authorities eg health, social care, education involved in providing support to children, this would not address the fact that the legal drivers for younger people’s continuing care are fundamentally different: for adults, the ‘primary health need’ test determines whether the NHS provides for all their needs, whereas in Children’s Continuing Care each agency remains responsible for meeting their own contribution to the care package. Accordingly, a separate children’s framework was preferred.

As part of the consideration of all the options, we are considering whether to issue the National Framework as good practice or to make it mandatory. It is realistic to suppose that if the use of the tool was voluntary not all PCTs and LAs would take it up, therefore the costs could be proportionately less than set out under the preferred option, and there would be less progress towards the benefits stated for the preferred option of consistency and equity across the country.

As part of the consultation we are inviting respondents to identify any other option not already considered.

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<sup>6</sup> <http://www.pssru.ac.uk/pdf/uc/uc2007/uc2007.pdf>

<sup>7</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_074459](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074459)

<sup>8</sup>

[http://www.barnardos.org.uk/breathing\\_space\\_community\\_support\\_of\\_children\\_on\\_long\\_term\\_ventilation\\_summary\\_1.pdf](http://www.barnardos.org.uk/breathing_space_community_support_of_children_on_long_term_ventilation_summary_1.pdf)

## Specific Impact Tests: Checklist

Use the table below to demonstrate how broadly you have considered the potential impacts of your policy options.

**Ensure that the results of any tests that impact on the cost-benefit analysis are contained within the main evidence base; other results may be annexed.**

Type of testing undertaken	<i>Results in Evidence Base?</i>	<i>Results annexed?</i>
Competition Assessment	No	No
Small Firms Impact Test	No	No
Legal Aid	No	No
Sustainable Development	No	No
Carbon Assessment	No	No
Other Environment	No	No
Health Impact Assessment	No	No
Race Equality	Yes	Yes
Disability Equality	Yes	Yes
Gender Equality	Yes	Yes
Human Rights	No	No
Rural Proofing	No	No

### **Costs of administering the Children's Continuing Care Framework: Specific Impact Tests:**

A National Framework for Children's Continuing Care is likely to promote equality for groups of children as described below but the policy has little scope for eliminating harassment or promoting good relations between different groups. It may however, reduce tensions by promoting a more transparent and consistent approach to decision-making

There is an inconsistent picture of data collection on disabled children at a local level. Whilst some LAs and PCTs are collecting good data, other areas lack the full data they need to underpin their planning and equality duties and ensure that progress is being made by disabled children and their families. (Aiming high for disabled children Report HM Treasury and the then Department for Education and Skills, May 2007). The Department for Schools and Families is working with the Department of Health to develop more consistent data on disability at both a national and local level on which agencies can plan, commission and provide appropriate services.

#### **Race:**

The proposed policy/practice could impact positively on people from Black and minority ethnic groups. Research by the Joseph Rowntree Foundation found unmet need for services in general by minority ethnic families to be higher than for white families ( Chamba, R et al (1999) On the edge: Minority ethnic families caring for severely disabled child ). This might be because of assumptions that minority ethnic families receive higher levels of family support so need less support from statutory services. Use of the National Framework for assessing need will make it harder to make assumptions about the family's ability to cope.

The National Framework concerns the assessment of need and will not address how care is subsequently delivered. However, the assessment will provide a better basis for dialogue with the family about their needs and how these can most appropriately be met.

The proposed policy/practice is thought likely to help to eliminate unjustifiable discrimination. The reasons for this are given above.

#### **Disability:**

Continuing care is needed over an extended period because of disability, accident or illness to address physical or mental health needs. Because a continuing care assessment will be triggered by a perceived need not by specific diagnosis, children and young people with disability will be treated in the same way as other children/young people who may have a continuing care need.

The proposed policy/practice is thought likely to help eliminate unjustifiable discrimination. The reasons for this are given above.

#### **Gender:**

The gender of a child or of their parents/carer is not relevant to the assessment of *need* so the proposed policy/practice is unlikely to impact differently on people because of their gender.

The proposed policy/practice is thought unlikely to help eliminate unjustifiable discrimination. The reasons for this are given above.

**Sexual Orientation:**

The sexual orientation of the child or of their parent/carer is not relevant to the assessment of continuing care *need* so the proposed policy/practice is unlikely to impact differently on people because of this.

The proposed policy/practice is thought unlikely to help eliminate unjustifiable discrimination. The reasons for this are given above.

**Age:**

The proposed policy/practice will only apply in respect of children and young people from birth to 18 years. The legal framework for older people is different and the NHS Continuing Care framework will apply.

The frameworks for children and young people have been aligned where possible, to help smooth the transition to adult services.

**Religion/Beliefs:**

The continuing care assessment is of the child's *need*. The religion or beliefs of the child/young person or their family could be relevant to the assessment of need or the way in which the need is met.

During discussion with stakeholders throughout the formulation of the National Framework no specific equality issues were raised but we would welcome any matters as part of the responses to this consultation.

## Costs of administering the Children's Continuing Care Framework:

Element to be costed	Assumptions	Indicative salary	Cost	Total cost including overheads @30%
Training one person from each PCT in use of the framework & DST	13 half-day training courses (one in each region and 2 in the larger regions) = 13 days @ band 8A salary (£37,000 to £44,500)	£40,750	£2,303	£2,994
	13 2-hr refresher courses (one in each region and 2 in the larger regions) = 13 half-days @ band 8A salary	£40,750	£1,152	£1,497
	cost of time trainees away from normal duties = 152 * 1.5 days @ band 8A salary	£40,750	£40,396	£40,396
Management briefings for 40 staff from each PCT/LA	2-hour sessions to give overview of new Framework in the workplace = 1 day per trainer per PCT @ band 8A salary	£40,750	£26,930	£35,010
	cost of time trainees away from normal duties = 38 trainees per PCT for 0.25 day @ £50,000	£50,000	£313,913	£313,913
	cost of time trainees away from normal duties = 2 trainees per LA for 0.25 day @ £50,000	£50,000	£16,522	£16,522
Practitioner training for 60 practitioners from each PCT/LA	3-hour hands-on sessions on using DST for nurses, doctors, social workers, occupational therapists, physiotherapists and anyone involved in assessment = 1 trainer per PCT for 2 days @ band 8A salary	£40,750	£53,861	£70,019
	cost of time practitioners away from normal duties = 55 trainees per PCT for 0.5 days @ £50,000	£50,000	£908,696	£908,696
	cost of time Social Workers away from normal duties = 5 trainees per LA for 0.5 days @ £45,000	£45,000	£74,348	£74,348
		14		

Additional 1 admin staff per PCT to service assessment and decision-making panels:	average one day per week per PCT @ mid-range EO salary; 1 admin staff in each of 152 PCTs	£23,405	£711,497	£711,497
IT costs:	£300 per PCT for licence to use database (download cost - database designed already)	-	£45,600	£45,600
Total cost for PCTs				<b>£2,129,622</b>
Total cost for LAs				<b>£90,870</b>
<b>Total cost:</b>				<b>£2,220,492</b>