

# Consultation Questionnaire

## Draft Statutory Guidance on Care and Support

### Consultation Questions

Section 2 : Values and Principles

**Question 1a: Was this section of the guidance clear and easy to understand?  
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 1b: How useful did you find this section of the guidance?  
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 1c: Do you have any further comments on this section of the guidance?**

*Some advice to help you to answer this question – Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?*

NHS Lothian notes the clarity of the information relating to the supported person's pathway in addition to the roles and responsibilities of each of the stakeholders.

## Draft Statutory Guidance on Care and Support

### Consultation Questions

Section 3: Values and Principles

**Question 2a: Was this section of the guidance clear and easy to understand?  
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 2b: How useful did you find this section of the guidance?  
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 2c: Do you have any further comments on this section of the guidance?**

*Some advice to help you to answer this question – Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?*

NHS Lothian believes that the values and principles laid out in the Guidance are an appropriate expectation of all health & social care professionals.

**Draft Statutory Guidance on Care and Support**

**Consultation Questions**

Section 4: Eligibility and Assessment

**Question 3a: Was this section of the guidance clear and easy to understand? (please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 3b: How useful did you find this section of the guidance? (please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 3c: Do you have any further comments on this section of the guidance?**

*Some advice to help you to answer this question – Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?*

NHS Lothian agrees that the assessment process must be driven by the personal outcomes of the individual rather than by the service itself. NHS Lothian has previous and current experience of testing out Self Directed Support within a healthcare organisation and we would be happy to share the findings and evaluation of our work to date.

The assessment process should be enabled through an open conversation between the individual, the professional and (where appropriate) carers / family members. An assessment should be reviewed following any change in circumstances to ensure the intervention continues to meet the individual's personal outcomes. This is clearly both for the individual patient but also the services benefit as there may be periods where the individual's condition does not require certain levels of support and it may be withdraw and re-instated appropriately following due and proper assessment of need.

NHS Lothian also agrees with the underpinning principles of collaboration, involvement and informed choice in the assessment process, in line with other drivers towards more person centred health care as detailed in NHS Lothian's Strategic Clinical Framework: Our Health, Our Future, in addition to the Healthcare Quality Standards, the 20:20 vision and the Person-centred Health & Social Care agenda.

## **Draft Statutory Guidance on Care and Support**

### **Consultation Questions**

#### Section 5 : Support Planning

This section of the guidance covered:

- general guidance on support planning
- risk
- resources
- the choices that must be made available to the supported person and
- information and support

**Question 4a: Was this section of the guidance clear and easy to understand?  
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 4b: How useful did you find this section of the guidance?  
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 4c: Do you have any further comments on this section of the guidance?**

*Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?*

NHS Lothian agrees that what is identified by the individual as being important to them should be given equal prominence in the support planning process as what is deemed by professionals to be important for them, with the emphasis placed firmly on the individual's abilities, not their disabilities.

#### Risk

The work of the NHS Lothian Self-directed Support (SDS) Test Site highlighted the importance of risk enablement in the planning process, and suggests that there will have to be a significant culture shift within statutory bodies to support staff to move from risk management to risk enablement / tolerance. Individuals must be given the support and information they require to participate in discussions and to make informed choices including the potential risk involved in the Support Plan they agree with their professional. The individual and professionals should also be mindful of the risk to achieving personal outcomes by doing nothing.

The Support Plan should be revisited following any change in circumstances to ensure that it continues to enable the individual's outcomes to be achieved, and the potential risks involved have been considered.

The planning process should be conducted using a solution focussed approach, starting with the personal outcomes identified by the individual with the intervention(s) then being agreed which will enable those outcomes to be realised.

The planning process should also be seen as an opportunity to identify and record unmet need, to give statutory services the opportunity to gauge the level of resourcing required to ensure that all personal outcomes are met (where possible) in the future.

#### The SDS Options

NHS Lothian notes the four options available to individuals via the SDS Act, where

only the option not currently available to an individual in terms of their healthcare being a Direct Payment.

#### Information & Support / Advocacy

NHS Lothian agrees that information and support should be provided to enable the individual to make an informed choice. This may require the input of independent advocacy providers; however Lothian Health Board believes that health and social care professionals are also capable of providing impartial information.

## **Draft Statutory Guidance on Care and Support**

### **Consultation Questions**

Section 6 : Monitoring and Review

**Question 5a: Was this section of the guidance clear and easy to understand? (please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 5b: How useful did you find this section of the guidance? (please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 5c: Do you have any further comments on this section of the guidance?**

*Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?*

As previously noted in this consultation response NHS Lothian agrees that a Support Plan should be monitored and reviewed by the social care professional, and where appropriate the health professional, to ensure that it continues to enable the outcomes identified by the individual to be met, including where there is a change in circumstances.

In addition, NHS Lothian suggests that where there is a jointly funded health and social care package, that health professionals are actively involved in any monitoring and review of that package of care. The Integration agenda and the eventual integration of teams will assist in this process improving over time.

## **Draft Statutory Guidance on Care and Support**

### **Consultation Questions**

#### Section 7 : Facilitating genuine choice for individuals

**Question 6a: Was this section of the guidance clear and easy to understand?  
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 6b: How useful did you find this section of the guidance?  
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 6c: Do you have any further comments on this section of the guidance?**

*Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?*

NHS Lothian has nothing to add but would endorse the principle of facilitating where appropriate and available the 'genuine' or 'best' choice of intervention, treatment or support is found for individuals.

## **Draft Statutory Guidance on Care and Support**

### **Consultation Questions**

#### Section 8 : The role of the NHS professional

**Question 7a: Was this section of the guidance clear and easy to understand?  
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 7b: How useful did you find this section of the guidance?  
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 7c: Do you have any further comments on this section of the guidance?**

*Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?*

that are more appropriate for statutory guidance rather than Regulations?

As previously stated NHS Lothian agrees with the underpinning principles of collaboration, involvement and informed choice which enable individuals to take a more active role in their health care. These principles also underpin NHS Lothian's Strategic Clinical Framework: *Our Health, Our Future*, in addition to the Healthcare Quality Standards, 20:20 vision and Person-centred Health & Social Care agenda.

The Board has made use of the powers provided to it through the Community Care (Joint Working etc.) (Scotland) Regulations 2002 (SSI 2002 No. 533) 'the 2002 Regulations', which enable Health Boards and Local Authorities to pool a jointly funded health and social care budget as a Direct Payment (via Local Authority mechanisms).

Where a jointly funded care package has been agreed, the key health professional should be fully involved in every stage of assessment, planning, monitoring and review.

Those personnel involved with the SDS agenda in NHS Lothian suggest that the more acute the health need the less appropriate SDS might be. We would therefore propose that SDS sits most appropriately in a Community Health setting, where people are living independently with long-term conditions but we must, and are, mindful of the total patient pathway which will mean for many periods of hospital admission.

In addition, our view based on the advice that we have received, is that drawing together a list of the health interventions which might be appropriate may not necessarily be helpful to health professionals, and instead suggest that the decision to delegate health care duties is not based on the particular intervention but on the delegated to individual's competence to carry out the intervention.

Where appropriate the delegee would be trained and supervised by NHS professionals until they were able to demonstrate competence in the intervention, and reviewed on a regular basis to ensure competence is maintained.

However, the Board agrees that the interventions listed in the guidance are appropriate to be delegated.

**Draft Statutory Guidance on Care and Support**

**Consultation Questions**

**Section 9.1 : Children and Families**

**Question 8a: Was this section of the guidance clear and easy to understand?  
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 8b: How useful did you find this section of the guidance?  
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 8c: Do you have any further comments on this section of the guidance?**

*Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?*

NHS Lothian agrees that a child should be supported to live as normal a life as possible and that the 'GIRFEC' principles should be followed to enable this.

The child should be supported to take a more active part in discussions regarding their care, with professionals ensuring that all possible methods are used to ensure that the personal outcomes of the child are at the centre of the processes.

The Board is also sensitive to the potential tensions this may create between professionals and parents / guardians; however the basic principals of the SDS Act must prevail with the child supported to identify their outcomes and their wishes being given increasing prominence as they transition from Children's to Adult Services.

The Board suggests that the transparency offered by the outcomes focused approach underpinning SDS processes may also offer another avenue re the challenges faced by children, their families and professionals through the transition period.

## **Draft Statutory Guidance on Care and Support**

### **Consultation Questions**

#### **Section 9.2 : Supported decision-making and circles of support**

**Question 9a: Was this section of the guidance clear and easy to understand?  
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 9b: How useful did you find this section of the guidance?  
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 9c: Do you have any further comments on this section of the guidance?**

*Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?*

NHS Lothian agrees that an individual must be given the information and support they require to make an informed choice. Adults and children who require support to make decisions on the options should not be disadvantaged by this.

However, the Board also accepts that due to an individual's limited capacity or communication, they may not be able to fully contribute to the decision making process and that in these circumstance, a family member or guardian's views should be sought, with the consent of the individual where possible.

In addition, it is suggested that it may be helpful to reinforce that the information needs not only to ensure that the individual is informed to make choices and act on those choices in relation to their chosen SDS option, but that they or their proxy are clearly informed of their rights for review etc, and that where necessary this is revisited within times frames that are supportive to the individual.

**Draft Statutory Guidance on Care and Support**

**Consultation Questions**

Section 9.3: Carers

**Question 10a: Was this section of the guidance clear and easy to understand?  
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 10b: How useful did you find this section of the guidance?  
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 10c: Do you have any further comments on this section of the guidance?**

*Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?*

NHS Lothian agrees that where a carer has been assessed as having care needs that the four SDS options should be made available to them, and that the carer should be supported to make an informed choice regarding the degree of choice and control they wish to have over that package of care.

In addition the Board welcomes

- the focus on an outcomes approach to assessment (s115)
- the recognition that by supporting carers that support from statutory agencies can be avoided or reduced
- the recognition of importance of putting 'in place the right support at the right time' (s118) for carers
- the acknowledgement that early preventative support can help lessen the negative impact of a caring role and is more cost effective (and less stressful) for both the carer and the person receiving care (s122)
- the recognition that carers who do not meet the eligibility criteria for a carer's assessment would still benefit from low level preventative support

However, the Board would welcome clarity on s120 which talks about advocacy for carers 'if appropriate'. Although the Caring Together document confirms the importance and value of advocacy for carers in their own right it should be noted that independent advocacy for carers is very limited with demand far exceeding capacity with many waiting lists closed.

## **Draft Statutory Guidance on Care and Support**

### **Consultation Questions**

#### Section 9.4: Direct payments

**Question 11a: Was this section of the guidance clear and easy to understand? (please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 11b: How useful did you find this section of the guidance? (please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 11c: Do you have any further comments on this section of the guidance?**

*Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?*

NHS Lothian agrees that the individual should be fully cognisant of the information regarding Direct Payments including the flexibility offered and responsibilities involved, and the circumstances where this option might be removed, before making an informed choice regarding this option.

## **Draft Statutory Guidance on Care and Support**

#### Section 9.5: Wider legal duties and strategic responsibilities

**Question 12a: Was this section of the guidance clear and easy to understand? (please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 12b: How useful did you find this section of the guidance? (please**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 12c: Do you have any further comments on this section of the guidance?**

*Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?*

NHS Lothian has nothing further to add.

## **Draft Statutory Guidance on Care and Support**

### **Consultation Questions – General Questions**

#### The Guidance document as a whole

#### **Question 13: Do you have any further general comments on the guidance?**

*For example, are there any gaps in terms of the topics covered by the guidance? Are there any major changes that you would recommend? Do you have any comments on the style and layout of the guidance, or the language used in the guidance?*

NHS Lothian has nothing further to add.

#### The costs and benefits arising from this guidance

#### **Question 14: Do you have any comments on the financial costs or benefits of the requirements set out in the guidance?**

*Can you identify any financial costs or benefits to individuals, local authorities, health boards, providers or any other person or organisation affected by the guidance. In considering the costs and benefits you may wish to consult the Business Regulatory Impact Assessment published for the Social Care (Self-directed Support) (Scotland) Act available at the following hyperlink:*

<http://www.scotland.gov.uk/Publications/2012/03/5525>

*We plan to update the BRIA in light of the comments and information from this consultation.*

NHS Lothian has nothing to add to the comments made in the final consultation on the SDS Bill in 2012, by its Medical Director, David Farquharson, who noted concern that although the evaluation of the Local Authority SDS test sites highlighted the need for leadership to drive SDS forward, there has been no resource allocated to Scotland's Health Boards in-line with the funding provided by Scottish Government to Scotland's local authorities, providers & user groups in 2011.

#### The equality and human rights impacts of the guidance

#### **Question 15 (a): Do you have any views on the impact of the guidance on any or all of the following equality categories:**

- i) age;**
- ii) disability**
- iii) gender;**
- iv) lesbian, gay, bisexual and transgender;**

- v) race, and;
- vi) religion and belief

*Some advice to help you to answer this question - By “equality impacts” we mean whether or not the guidance will affect certain groups in a positive or a negative way. In considering the impacts you may wish to consult the Equality Impact Assessment published for the Social Care (Self-directed Support) (Scotland) Act available at the following hyperlink:*

<http://www.scotland.gov.uk/Publications/2012/03/9876>

*We plan to update the Equality Impact Assessment in light of the comments and information from this consultation.*

NHS Lothian believes that this guidance will impact positively on the groups defined by age or disability, and will have a neutral impact on the others listed.

### **Question 15 (b): Do you have any views on the impact of the guidance on human rights?**

For more information about human rights please see the Scottish Human Rights Commission’s website at:

<http://www.scottishhumanrights.com/abouthumanrights/whatarehumanrights>

NHS Lothian believes that the person-centred ethos of the guidance will impact positively on human rights.

## **Consultation Questionnaire**

### **Draft Regulations**

#### **Consultation Questions**

#### **Question 1: What are your views on Part 2 of the draft Regulations (calculation, payment and termination of direct payments)?**

Lothian Health Board is sensitive to the concept of means testing, as this is only a consideration in health care when an individual is being placed in a care home. The Board seeks clarity regarding the requirements that might be placed on Health Boards following the integration of health and social care.

#### **Question 2: What are your views on Part 3 of the draft Regulations (appropriate/inappropriate circumstances for the employment of close relatives)?**

NHS Lothian agrees with the examples given by Scottish Government regarding where it is appropriate for a family member to be employed to care for a close

relative. However, The Board suggests that the emphasis is on the particular circumstances of the family in determining the appropriateness of a family member taking on the role of paid carer.

The Board suggests that a further issue is how the local authorities can 'knowingly' make any informed decision regarding the appropriateness of this situation and how this will be reviewed to ensure the outcomes of the individual continue to be met, particularly where the condition of person doing the 'commissioning' deteriorates

In addition, the Board is sensitive to the tensions that this employer / employee dynamic might cause in a family, and suggests that families are supported to make an informed choice regarding the pros and cons of going down this route.

**Question 3: What are your views on Regulation 11 which deems individuals who are placed under a variety of criminal justice orders to be ineligible to receive direct payments?**

For example, is it appropriate to impose the exclusions listed in Regulation 11? Are there any persons not listed in regulation 11 to whom it would be inappropriate to offer the option of a direct payment?

NHS Lothian broadly agrees with the examples given by Scottish Government but would seek the assurance of a process that says that those defined under section 11 are reviewed on an individual basis and where the case is strong i.e. the person is drug or alcohol free and has been in abstinence for X period that they may be reconsidered for SDS payments.

**Question 4: What are your views on restricting access to direct payments for those who are homeless, those who are fleeing domestic abuse or those who require support in relation to drug or alcohol addiction?**

NHS Lothian agrees that there needs to be scope for a professional's judgement to be brought to bear where the identified groups are concerned. However, the Board seeks clarity regarding the rationale regarding the groups listed in regulation 12 and the definition of 'relevant professional' in respect of this and other decision making processes.

**Question 5: What are your views on restricting access to direct payments in relation to the provision of long-term residential care?**

This question was raised during the initial consultations on a draft SDS Bill. The Scottish Government would like to invite detailed views before making a final decision prior to the laying of the Regulations before the Scottish Parliament. Should the restriction be removed from the final regulations, thereby allowing direct payments for residential care? Or should it be retained? Please provide reasons as to your support or opposition to requiring authorities to provide direct payments for residential care.

NHS Lothian agrees that use of the funding for long term residential care is appropriate. However, the Board suggests that the issue is that of 'appropriate', and that each case should be judged on its own merits and uniqueness.

**Question 6: The draft Regulations do not specify circumstances where the direct payment option should be unavailable for care and support to children/families. *Should* there be specific restrictions on choice of support in relation to children/families support (i.e. support provided under Section 22 of the Children (Scotland) Act 1995) and should these restrictions apply to the direct payment only, or to other options as well?**

Children and Families should always have access to the full range of services and choices of support that meet their needs, as identified within any joint care plan. Any restrictions should only apply where consistent with the principles and statutory duties being considered under the new Children and Young People's Bill and with the Rights Of The Child

**Question 7: Do you have any further comments on the draft Regulations?**

For example, are there any gaps in terms of the topics covered by the Regulations? Are there any major changes that you would recommend? Are there any topics that are more appropriate for statutory guidance rather than Regulations?

NHS Lothian would like clarification regarding how the legislation deals with issues such as dementia and degenerative neurological conditions and how it takes into account the periods of remission which individuals with these conditions will have?

## **Draft Regulations**

### **Consultation Questions – General Questions**

The costs and benefits arising from these regulations

**Question 8 : Do you have any comments on the financial costs or benefits of the Regulations?**

Can you identify any financial costs or benefits to individuals, local authorities, health boards, providers or any other person or organisation affected by the Regulations. In considering the costs and benefits you may wish to consult the Business Regulatory Impact Assessment published for the Social Care (Self-directed Support) (Scotland) Act available at the following hyperlink:

<http://www.scotland.gov.uk/Publications/2012/03/5525>

We plan to update the BRIA in light of the comments and information from this consultation.

NHS Lothian seeks clarification regarding how the financial costs or benefits of the Regulations will be dealt with through the establishment of health and social care partnerships, including where the responsibility for each individual's health and social care needs are best met.

The Board recognises that the financial processes in the health and social care partnerships will take time to be established and to address all aspects of care but suggests that the idea that they would have pulled/joint budgets and would be responsible for meeting need appropriately is the way in which the management of the money and the process should be managed.

The equality and human rights impacts of the regulations

**Question 9 (a): Do you have any views on the impact of the Regulations on any or all of the following equality categories:**

- i) age;**
- ii) disability**
- iii) gender;**
- iv) lesbian, gay, bisexual and transgender;**
- v) race, and;**
- vi) religion and belief**

By “equality impacts” we mean whether or not, and in what ways, the Regulations will affect certain groups, and whether they will impact on those groups in a positive or a negative way. In considering the impacts you may wish to consult the Equality Impact Assessment published for the Social Care (Self-directed Support) (Scotland) Act 2013, available at the following hyperlink:

<http://www.scotland.gov.uk/Publications/2012/03/9876>

We plan to update the Equality Impact Assessment in light of this consultation.

NHS Lothian believes that this guidance will impact positively on the groups defined by age or disability, and will have a neutral impact on the others listed.

**Question 9 (b): Do you have any views on the impact of the Regulations on human rights?**

For more information about human rights please see the Scottish Human Rights Commission’s website at:

<http://www.scottishhumanrights.com/abouthumanrights/whatarehumanrights>

NHS Lothian has nothing further to add but would make the assumption that the application of SDS would not knowingly impair or impinge any individuals human rights.