



The Scottish  
Government  
Riaghaltas na h-Alba

## National Care Standards Review Public Consultation

### RESPONDENT INFORMATION FORM

**Please Note** this form **must** be returned with your response to ensure that we handle your response appropriately

#### 1. Name/Organisation

##### Organisation Name

Down's Syndrome Scotland

Title Mr  Ms  Mrs  Miss  Dr  Please tick as appropriate

##### Surname

Le Noan

##### Forename

Rachel

#### 2. Postal Address

158-160 Balgreen Road

Edinburgh

Postcode EH11 3AU

Phone 01313137452

Email Rachel@dsscotland.org.uk

#### 3. Permissions - I am responding as...

Individual / Group/Organisation

Please tick as appropriate

- (a) Do you agree to your response being made available to the public (in Scottish Government library and/or on the Scottish Government web site)?

**Please tick as appropriate**

Yes  No

- (b) Where confidentiality is not requested, we will make your responses available to the public on the following basis

**Please tick ONE of the following boxes**

Yes, make my response, name and address all

- (c) The name and address of your organisation **will be** made available to the public (in the Scottish Government library and/or on the Scottish Government web site).

Are you content for your **response** to be made available?

**Please tick as appropriate**

Yes  No

available

*or*

Yes, make my response available, but not my name and address

*or*

Yes, make my response and name available, but not my address

**(d)** We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

***Please tick as appropriate***

**Yes**

**No**

## CONSULTATION QUESTIONS

### Question 1

Do you think that the new National Care Standards should be grounded in human rights?

Yes.

### Question 2

a. Do you agree that overarching quality standards should be developed for all health and social care in Scotland?

Yes.

However the distinction between overarching quality standards and the set of general quality standards is presently difficult to understand. According to the consultation document, the new standards, both overarching and general, should apply to all care and health services but the overarching standards themselves are supposed to reflect human rights principles. As a result a distinction between quality standards and human rights principles might be more appropriate and better understood than 'overarching v general quality standards'. We would thus suggest to change the name of the so-called 'overarching quality standards' to 'overarching human rights principles or duties'.

b. Do you agree that the overarching quality standards should set out essential requirements based on human rights?

Yes.

More information is however required on how these principles would be made accessible to all service users (of all age groups) and service providers. It would also be helpful to know more about how such requirements will be monitored to ensure the best quality of care and health services throughout the country.

c. Do you agree that the current National Care Standards should be streamlined and a set of general standards developed that would sit below the overarching standards and apply to all services?

Yes, provided that the distinction between overarching standards and general standards is better defined as outlined in our answer to question 2.a.

d. Do you think general standards should set out essential requirements and aspirational elements?

No.

The consultation has the objective to simplify care standards but the nature of the general standards, as outlined in the present document, is confusing. The current proposition of having essential requirements and aspirational elements fails to convince us that this would lead to a simplification of care standards.

DSS is of the view that one set of essential requirements would be easier to understand and to implement across all services. It is our understanding that the general standards will work towards achieving human rights based principles of care. Consequently, we would advise that the level of the general standards should be consistent with these principles and for essential requirements to be of high calibre from the very beginning.

e. Do you agree that a suite of specific standards are developed for particular aspects of care, circumstances or need?

Yes.

With regard to specific care standards for people with learning disabilities, we would therefore welcome further advice as to what the specific care standards for people with learning disabilities would cover and how they would be designed.

### **Question 3**

a. What are your views on how standards should be written?

We agree with the view that standards should be appropriately worded and contain explanations on the rights of people using services and responsibilities of service providers. In order for this information to be accessible to all, appropriate formats should be used (easy read

literature for example) and adequate resources agreed so that users understand what their rights are and what they can expect from services.

When establishing new standards, it is essential not only to involve service providers but also engage with service users, including people with Down's syndrome and their families. Their experiences will help improving care and health services but these experiences need to truly be taken into account in the decision-making process, and not simply be used as a 'box ticking exercise'.

b. What are your views on the example of how the rights and entitlements of people using services and the responsibilities of service providers could be set out?

The example looks fine provided that different formats are made available to all age groups.

#### **Question 4**

a. Do you think the Care Inspectorate and Healthcare Improvement Scotland should hold services they regulate to account for meeting the proposed overarching standards, the general standards and the suite of specific standards?

Yes.

Healthcare Improvement Scotland's mission is 'to be the recognised healthcare improvement organisation which drives the delivery of world-class person-centred healthcare in Scotland' (see HIS Strategy 2014-2020). One could therefore assume that HIS and the Care Inspectorate are the best agencies to hold services to account in order to deliver the best possible outcomes for social and healthcare in Scotland.

b. How should we ensure that services not regulated by the Care Inspectorate and Health Improvement Scotland comply with the new standards?

Consistency in the quality of health and social care across Scotland is primordial to ensure that the rights of all service users are respected. It would therefore be helpful to have the same bodies monitoring both regulated and non-regulated services thus guaranteeing that all services are subject to the same criteria in complying with the new standards.

c. We suggest that the Care Inspectorate and Healthcare Improvement Scotland, consulting with others, should develop the suite of specific standards. Do you agree with this?

Yes.

Down's Syndrome Scotland is of the view that consulting with third sector organisations and involving users of services in the process should be another priority. Engaging with people with Down's syndrome and their families would allow for the specific standards to meet essential needs and thus improve the quality of life of service users.

### **Question 5**

a. Please tell us about any potential impacts, either positive or negative, you feel any of the proposals set out in this consultation paper may have on particular groups of people, with reference to the 'protected characteristics' listed above.

As a charity supporting people with Down's syndrome, we support human rights based standards of care and believe these will have a positive impact on the lives of our members. Nevertheless to ensure that human rights are not only used as a 'token' concept to promote a more equal society, professionals will need to receive adequate training not only to understand the new standards but also to engage with all service users while standards are being developed. In order to fully involve children and adults with Down's syndrome in this process, all published material would also need to be available in a variety of formats.

b. Please tell us about any potential costs or savings that may occur as a result of the proposals set out in this consultation paper and any increase or reduction in the burden of regulation for any sector. Please be as specific as possible.

Further to our answer to Question 5.a, we would anticipate that costs would incur with regard to publishing information in various formats and training costs for staff.

### **Question 6**

Please tell us if there is anything else you wish us to consider in the review of the National Care Standards that is not covered elsewhere in the consultation paper.

Down's Syndrome Scotland believes that prevention and early intervention should become part of the general quality standards, along with participation, personalisation etc. It is important to recognise that as well as targeting identified needs, services should be geared towards preventing further needs from arising in the first place. Prevention and early intervention have been supported by the Scottish Government in recent years with the view to tackle inequalities in Scottish society. Both prevention and the idea of early intervention are relevant to the wellbeing of children and adults with Down's syndrome. Consequently it is important for these concepts to be included and acknowledged in the new national care standards.

## How to respond

We are inviting responses to this consultation paper by 17<sup>th</sup> September 2014. Please send your response with the completed Respondent Information Form to [nationalcaresstandardsreview@scotland.gsi.gov.uk](mailto:nationalcaresstandardsreview@scotland.gsi.gov.uk)

or to:

Carly Nimmo  
Mental Health and Protection of Rights Division  
The Scottish Government  
Area 3ER, St Andrews House  
Edinburgh  
EH1 3DG

We would be grateful if you would **use the consultation questionnaire provided in the consultation document or clearly indicate in your response which questions or parts of the consultation paper you are responding to** as this will aid analysis of the responses received.

This consultation, and all other Scottish Government consultation exercises, can be viewed online on the consultation web pages of the Scottish Government website at <http://www.scotland.gov.uk/consultations>

## Handling your response

We need to know how you wish your response to be handled and, in particular, whether you are happy for your response to be made public. Please complete and return the Respondent Information Form as this will ensure that we treat your response appropriately. If you ask for your response not to be published we will regard it as confidential, and we will treat it accordingly.

All respondents should be aware that the Scottish Government are subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.



## **Alternative formats and languages**

If you require a copy of this paper in an alternative format or different language please contact us at the address above.

## **Next steps in the process**

If you tell us we can make your response public we will put it in the Scottish Government Library and on the Scottish Government consultation web pages. We will check all responses where agreement to publish has been given for any wording that might be harmful to others before putting them in the library or on the website. If you would like to see the responses please contact the Scottish Government Library on 0131 244 4565. Responses can be copied and sent to you, but a charge may be made for this service.

## **What happens next?**

Following the closing date, all responses will be analysed and considered along with any other available evidence to help us reach a decision about how to proceed with the review of National Care Standards. We will issue a report on this consultation process which will be published on the Scottish Government's website at:  
<http://www.scotland.gov.uk/Publications/Recent>

Further consultation on the detailed content of the new standards will take place during 2014-15.

## **Comments and complaints**

If you have any comments about how this consultation exercise has been conducted, please send them to:

Lindsay Liddle  
Mental Health and Protection of Rights Division  
The Scottish Government  
Area 3ER, St Andrews House  
Edinburgh  
EH1 3DG