

# **National Delivery Plan**

## **For Children and Young People's Specialist Services in Scotland In Scotland**

### **Response Sheet**

This consultation exercise is intended to help shape the provision of health care and other services for children and young people in Scotland. This response paper should be read in conjunction with the report *National Delivery Plan – for Children and Young People's Specialist Services in Scotland*

**You need not comment on all of the content of the document and can focus on those areas in which you have a particular interest.**

## **Responding to this consultation paper**

We are inviting written responses to this consultation paper by **Tuesday 27th May 2008**. Please send your response to: [childandmaternalhealth@scotland.gsi.gov.uk](mailto:childandmaternalhealth@scotland.gsi.gov.uk) , or via the Internet, or to

The Child and Maternal Health Division  
Scottish Government Health Department  
Ground Rear  
St Andrew's House  
Edinburgh EH1 3DG  
Fax: 0131 244 4775

## **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 If you ask for your response not to be published we will regard it as confidential, and we will treat it accordingly.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.

## **Next steps in the process**

Where respondents have given permission for their response to be made public (see the attached Respondent Information Form), these will be made available to the public in the Scottish Government Library by end July 2008. We will check all responses where agreement to publish has been given for any potentially defamatory material before logging them in the library or placing them on the website. You can make arrangements to view responses by contacting the SG 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. The draft National Delivery Plan will be adjusted to reflect comments received and the intention is that it will be published in the summer of 2008 as guidance from the Scottish Government.

## **Comments and complaints**

If you have any queries or comments about how this consultation exercise has been conducted, please send them to: Gillian Garvie, The Child and Maternal Health Division , Scottish Government Health Department, Ground Rear, St Andrew's House, Edinburgh EH1 3DG. E-mail: [gillian.garvie@scotland.gsi.gov.uk](mailto:gillian.garvie@scotland.gsi.gov.uk). If you would like this response sheet in another format or language, please contact Gillian Garvie on 0131 244 4086.

## RESPONDENT INFORMATION FORM: National Delivery Plan – for Children and Young People’s Specialist Services in Scotland

Please complete the details below and return it with your response. This will help ensure we handle your response appropriately. Thank you for your help.

Name: Genetic Interest Group (Scotland)

Postal Address: University of Edinburgh  
St John's Land  
Holyrood Road  
Edinburgh  
EH8 8AQ

1. Are you responding: (please tick one box)
- (a) as an individual  go to Q2a/b and then Q4
- (b) **on behalf of** a group/organisation  go to Q3 and then Q4

### INDIVIDUALS

- 2a. Do you agree to your response being made available to the public (in Scottish Government library and/or on the Scottish Government website)?

Yes (go to 2b below)

No, not at all  We will treat your response as confidential

- 2b. **Where confidentiality is not requested**, we will make your response available to the public on the following basis (**please tick one** of the following boxes)

Yes, make my response, name and address all available

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

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

### ON BEHALF OF GROUPS OR ORGANISATIONS:

- 3 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 website). Are you also content for your **response** to be made available?

Yes

No  We will treat your response as confidential

### SHARING RESPONSES/FUTURE ENGAGEMENT

- 4 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 the Scottish Government to contact you again in the future in relation to this consultation response?

Yes

# **National Delivery Plan – for Children and Young People’s Specialist Services in Scotland**

If you wish to comment on the National Delivery Plan please use this response sheet and use the consultation document.

## **Section 1- Introduction**

1. We would welcome your views on the issues and recommendations raised in this section.

The Genetic Interest Group would welcome a review of the process for the provisions of aids, adaptations and equipment for children and young people with specialist health needs. Currently, the entitlement to Home Improvement Grants for Scottish families caring for children affected by disabling genetic conditions is discretionary and conditional on the type of accommodation they live in as well as being means-tested. This compares unfavourably with families living in England and Wales who are entitled to Disabled Facility Grants of £25,000 and £30,000 respectively.

## **Section 2 - Why Change is Needed Now**

2. Do you think that the key challenges facing specialist children’s services are sufficiently described.

No comment.

3. Are there any additional challenges that you think should be highlighted.

The Genetic Interest Group would like to take this opportunity to stress the value of patient contribution to the delivery of healthcare. Patients have a unique perspective and knowledge of their condition, and should be allowed to contribute to care provision decisions as much as possible.

The Genetic Interest Group has a Patient Engagement Officer in Scotland, Claire Cotterhill (claire@gig.org.uk), who is able to provide support, assistance and advice with this process.

DEBRA (Dystrophic Epidermolysis Bullosa Research Association) is a member of the Genetic Interest Group. We have seen their contribution to this consultation and would like to briefly refer to the issue of dressings for Epidermolysis Bullosa patients. This is an example of how consultation with patients at an early stage would have delivered a better quality of care to patients, and avoided unnecessary concern and distress for patients during the care provision process.

## **Section 3 - The Way Forward – A National Delivery Plan**

4. We would welcome your views on this aspect of the plan.

No comment.

## Section 4 - Making it Happen - Supporting Service Delivery

### CHILDREN'S CANCER SERVICES

5. We would welcome your views on the recommendations for the future of Children's Cancer Services in Scotland.

No comment.

### CYSTIC FIBROSIS AND INHERITED METABOLIC DISEASES

6. We would welcome your views on the approach being proposed for cystic fibrosis.

A National Managed Network is proposed for Inherited Metabolic Diseases. This should encompass Cystic Fibrosis. This would allow best practice to be shared from a well understood inherited metabolic condition to inherited metabolic conditions that are less well understood.

7. We would welcome your views on the approach being proposed for inherited metabolic disease.

The group of conditions described by the term "inherited metabolic disease" is extremely broad and heterogenous. The term encompasses conditions with many hundreds of patients in Scotland, and conditions with fewer than ten patients.

Cystic Fibrosis is an inherited metabolic disease itself; it is one of the best understood inherited metabolic conditions: cases are diagnosed quickly, and care pathways are well understood by health professionals. This situation should be taken as an example of the high level of care that can be achieved for this kind of condition. Every patient with an inherited metabolic condition should be availed of the best possible quality of care.

The priorities of a National Managed Network should be to ensure:

- a. expert advice is available to clinicians for all conditions, however rare they may be;
- b. the current variability of knowledge of conditions and quality of care is addressed and normalised as soon as possible.

### PAEDIATRIC RHEUMATOLOGY

8. We would welcome your views on the recommendation for the future of Children's Rheumatology services in Scotland.

**Scottish Muscle Network:** In our work in other countries in the United Kingdom, the Genetic Interest Group frequently point to the Scottish Muscle Network (<http://www.gla.ac.uk/muscle/index.html>) as an example of a clinical network that provides essential advice to patients and professionals.

This model should be seen as an excellent example of how to deal with rare conditions. Patients with Duchenne Muscular Dystrophy (DMD) are supported by the Scottish Muscular Networks.

### GENERAL SURGERY OF CHILDHOOD

9. We would welcome your views on the recommendations outlined for the provision of General Surgery of childhood.

No comment.

## **ROLE OF NETWORKS**

10. We would welcome your views on the recommendations outlined in this section.

Through our own research with patients (“Family Route Map Project – a report of a series of six focus groups, March 2007” [http://www.gig.org.uk/docs/FocusGroupReport\\_final\\_colour.pdf](http://www.gig.org.uk/docs/FocusGroupReport_final_colour.pdf) ) GIG has found that one of the major barriers to receiving good care is the lack of communication between various healthcare professionals who may not be based in the same hospital. The issue of having to “continually repeat yourself” to different professionals (who often know less about the rare condition than the patient) is a real one that has an impact on the care patients receive. GIG therefore proposes that integrated care should be provided for patients of complex conditions that require care from more than one of the traditional specialisms of healthcare provision in Scotland.

**The Genetic Interest Group strongly supports the introduction of *Managed Clinical Networks* and *Managed Service Networks* for the reasons outlined below:**

Many rare genetic disorders are complex, affecting many of the body’s systems. They also can display a wide variation in their presentation, although the vast majority result in severe, chronic ill health, often progressive disability and sometimes (very) premature death.

Families affected by these rare conditions often experience additional problems arising from the organisation and delivery of health services that make access to appropriate health care and support more difficult to secure than it needs to be. As a consequence of the small numbers affected by any one disorder, expertise in the diagnosis and management of a specific condition is scarce. This factor could be more acute for patients in remote areas who live long distances from centres of expertise. Normal community-based services are often not able to provide speedy, accurate diagnosis or an integrated and appropriate package of intervention and support that will give the best chance for the patient.

Patients with complex multi-system genetic disorders are frequently heavy users of the NHS. For example, patients with Alström’s Syndrome (about 35 families known in the UK) require support from ophthalmologists, audiologists, cardiologists, diabetologists, dieticians, endocrinologists and others. At a more common end of the spectrum patients with Neurofibromatosis 1 (NF1) (2100 in Scotland) may need neurologists, ophthalmologists, orthopaedic surgery, cranio-facial surgery, dermatologists, plastic surgery, psychiatry, oncology and educational psychology.

If the services provided are not integrated, optimising the outcome for the patients can be at best difficult – for example, in the case of Alström’s Syndrome the proper management of patients’ unusual type of diabetes has an impact on the cardiological options. In the case of NF the optic gliomas that sometimes occur behave differently from sporadic optic gliomas in patients without NF, and thus need different management. (The more usual drug treatment does not work. If it is given in error, it is deleterious to the patient’s condition and a waste of resources.) Many other similar examples could be provided for other conditions.

Integrated care for rare genetic disorders, how it can be provided As a reflection of the difficulties experienced by families with “their” condition, many patient support groups have invested considerable sums of money (derived from the voluntary fundraising efforts of their members, most of whom are directly affected) in providing a range of services and support. At the most basic level this can be a volunteer helpline dispensing practical advice and information. Other groups have sophisticated networks and employ professional staff. This investment, built on voluntary income, is increasingly proving unsustainable, and many charitably funded services are proving increasingly frail.

## Infrastructure

Depending on the nature and population frequency of the conditions, integrated care could be provided as follows:

1. **Specialist centres / multidisciplinary clinics** with a variety of expertise to allow patients to see all the specialists relevant to their condition at a single site, on a single day. This system would be mutually beneficial to patients, who will receive a high quality of care on a convenient basis; and to health professionals, especially those with a research interest in the condition. The centres or clinics could be grouped by conditions that require similar specialisms for the rarest of disorders, rather than focusing on one particular condition per clinic.
2. **Genetic Care Coordinators** who would take a key role in helping patients access care e.g. NF, Muscular Dystrophy (MD) and ataxia. The specialist advisor would work closely with specialist healthcare professionals to ensure that patients get appropriate care, and offer emotional and practical support on social and educational issues associated with the disorder. They would become the patient's first port of call, reducing the burden on GPs and health visitors; and they would act as a source of information for healthcare professionals. This system should be funded by the NHS, but in the past patient organisations have stepped in to fill the gap; both the NF Association and the MD Campaign were forced to cut the number of specialist advisers for the UK in the past due to financial difficulty.
3. **Genetic Disease Registries** where a health professional is in charge of recalling patients once (or possibly twice) a year to the genetic centre or multidisciplinary clinic to undertake a similar role to the Genetic Care Coordinators mentioned in point two. Registries are established successfully in various areas of the UK in genetic centres.

No single model will fit all disorders. For some the specialist multi-disciplinary clinic, together with a Genetic Care Coordinator is a good approach. For others this is not practical and the employment only of a Genetic Care Coordinator is more appropriate.

## Funding

Many of the charitable support groups offer several of the care models. All find funding difficult. The rarity of these disorders, and hence the smallness of each of the charities, presents particular challenges in maintaining continuity and quality of services.

## Patient Input

The Genetic Interest Group's strong view on the importance of Managed Clinical and/or Service Networks arises from extensive consultation with patients. Patients will have often developed unique expertise in the condition which affects them. One of the findings from our work with patients, mentioned above, is that the type and specification of a network will vary from condition to condition. We believe patients should have extensive input on the design of networks aimed at improving their care; healthcare providers should be allowed to work with each other and patients to develop policy matched to need.

The Genetic Interest Group has a Patient Engagement Officer in Scotland, Claire Cotterhill (claire@gig.org.uk), who is able to provide support, assistance and advice with this process.

## Managed Service Networks

11. We would welcome your views on the concept of a service network model for specialist services for children.

Please refer to our answer to question 10, for a broad discussion of the two concepts of Managed Service Networks and Managed Clinical Networks. In many cases elements of each concept may be applicable to care of a certain condition.

## Telemedicine

12. We would welcome your views on the recommendations for telemedicine.

The Genetic Interest Group believes that Telemedicine is essential to support effective integrated care for patients who live in remote communities. This innovative use of technology benefits the patient by reducing the anxiety and cost associated with long-distance travel.

## PLANNING AND COMMISSIONING

13. We would welcome any comments you may have on the recommendations in this section of the National Delivery Plan.

No comment.

## WORKFORCE

14. We would welcome your views on the recommendations outlined regarding workforce, education and training.

The Genetic Interest Group supports funding mechanisms that will allow staffing to reflect patient needs across Scotland. We are happy to provide further information on this issue, please contact Gillian Scott, Development Officer ([gillian@gig.org.uk](mailto:gillian@gig.org.uk)).

In addition, please refer to point two in the Infrastructure section of our response to question 10, for a discussion of the benefits that Genetic Care Coordinators can provide to patients.

## IMPROVING QUALITY - PERFORMANCE MANAGEMENT

15. Are the proposed recommendations sufficient to monitor the implementation of the National Delivery Plan.

No comment.

16. We would welcome your views on the establishment of a:

- Child Health Collaborative programme
- Child Health Alliance

No comment.

## SECTION 5 Age Appropriate Care

17. Are there any aspects of age appropriate care provision not sufficiently covered within either the text or recommendations.

No comment.