The Adoption (Disclosure of Medical Information about Natural Parents) (Scotland) Regulations 2009

CONSULTATION ON DRAFT REGULATIONS

The Scottish Government

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INTRODUCTION

This document accompanies the draft Adoption (Disclosure of Medical Information about Natural Parents) (Scotland) Regulations 2009. It sets out the policy behind the draft Regulations and seeks your comments on a number of issues within the Regulations. The consultation period runs until 28 January 2009.

There are specific questions on which we seek your views and these are highlighted in the document. However, we welcome comments on all of the proposals.

This document is primarily being distributed electronically and is available on the Scottish Government web-site at

www.scotland.gov.uk/adoptionmedicaldisclosure

If, however, you would wish to be sent the document in photocopy please contact

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or e-mail <u>adoptionregulations@scotland.gsi.gov.uk</u> to arrange for a copy or copies to be sent to you.

Please send your response electronically to the above address or in hard copy to

Adoption Support Regulations Consultation, 2-A(N) Victoria Quay, EDINBURGH, EH6 6QQ

Please complete the details on the respondent information form at the end of this document and return it with your response. This will help ensure we handle your response appropriately. The form should be printed first to enable completion and then either scanned and emailed or sent as a hard copy (depending on how you intend to send your response). Thank you for your help.

BACKGROUND

The Adoption and Children (Scotland) Act 2007 ('the 2007 Act') introduced a range of reforms into the law relating to adoption of, and permanent care for, children who cannot remain with their birth families.

Once the new legislation is commenced, the existing legislation – the Adoption (Scotland) Act 1978 ('the 1978 Act') – will be repealed, except to the extent necessary to maintain the legality of those adoptions that have already been made under it. One consequence of this is that existing Regulations made under the 1978 Act will no longer be valid. For that reason new Regulations require to be put in place to restate, and amend, extend and improve, existing Regulations. In doing this account will be taken of the report from the Adoption Policy Review Group (APRG) Adoption: Better Choices for Our Children, which has already shaped the 2007 Act itself.

The present consultation paper deals with the draft Adoption (Disclosure of Medical Information about Natural Parents) (Scotland) Regulations 2009. The Adoption (Disclosure of Medical Information about Natural Parents) (Scotland) Regulations 2009 are subject to affirmative parliamentary procedure and therefore cannot be combined with the Adoption Information (Scotland) Regulations. However, they can be combined with the Adoption (Disclosure of information) Regulations and views on whether they should form a combined set of regulations are appreciated.

While there is provision for the collection of medical information when considering a child for adoption (the currently and future Adoption Agencies Regulations and Adoption Information Regulations), practitioners indicated that access to medical information on the birth parents and child is necessary to plan properly for the child. The APRG identified 3 situations where it proves difficult, in practice, to access medical information: where there is no consent because birth parents have never been asked; where there is no consent because birth parents have disappeared or are otherwise absent and therefore cannot be asked; where there is no consent because birth parents have refused to give it. Guidance from the General Medical Council indicates that medical information on the Natural parents may be disclosed where there is a clear need for this disclosure in the interest of the child's welfare. however there are occasions where this is not forthcoming. These regulations are intended to address this issue where consent is not achievable.

Regulations are intended to supplement primary legislation – in this case the 2007 Act – so they do not generally repeat provision already there. To aid full consideration, therefore, the most relevant provisions in the 2007 Act are reproduced for ease of reference at Annex B.

The full text of the 2007 Act may be found at:

http://www.opsi.gov.uk/legislation/scotland/acts2007/asp 20070004 en 1

The APRG Report Adoption: Better Choices for Our Children may be found at:

http://www.scotland.gov.uk/Publications/2005/06/27140607/06107

COMMENTARY

THE ADOPTION (DISCLOSURE OF MEDICAL INFORMATION ABOUT NATURAL PARENTS) (SCOTLAND) REGULATIONS 2009

Regulations 1-3

1. Citation and commencement

These Regulations may be cited as the Adoption (Disclosure of Medical Information about Natural Parents) (Scotland) Regulations 2009 and come into force on 2009.

2. Interpretation

In these regulations-

"the Act" means the Adoption and Children (Scotland) Act 2007; and "adoptive parents" means persons who are to or may adopt, or have adopted, the relevant child.

3. Application

These regulations apply subject to-

- (a) the Adoption Agencies (Scotland) Regulations 2009;
- (b) the Adoption Information (Scotland) Regulations 2009; and
- (c) the Adoption (Disclosure of Information) (Scotland) Regulations 2009.

Regulations 1 and 2 provide for the commencement date and definitions to be used throughout the following Regulations. Where an expression is used in these Regulations it will have the same definition as in the Act unless a separate definition is provided.

Regulation 3 makes this set of regulations subsequent to the

- Adoption Agencies (Scotland) Regulations
 (http://www.scotland.gov.uk/Publications/2008/07/01141306/0),
- Adoption Information (Scotland) Regulations and
- Adoption (Disclosure of Information) (Scotland) Regulations (http://www.scotland.gov.uk/Publications/2008/08/12093247/0).

The regulation will be updated if these regulations are combined. The purpose of this regulation is to ensure that the Adoption (Disclosure of Medical Information about Natural Parents) (Scotland) Regulations are not the first and only route used by adoption agencies to access medical information. In the first instance adoption agencies should attempt to collect this information with the consent of the natural parents when preparing the adoption case. Where consent is withheld and no other attempt to collect this information has been successful these regulations will place a duty on GP's to disclose only the information indicated in these regulations.

These regulations specifically deal with the disclosure of medical information while an adoption agency is gathering this information. It is our view that the regulations

that deal specifically with the collection of information (the Adoption Information (Scotland) Regulations), the processes of adoption (the Adoption Agencies (Scotland) Regulations) and the disclosure of information on an adoption record (the Adoption (Disclosure of Information) (Scotland) Regulations) address the more general provisions relating to adoption information.

As an example, the draft Adoption Agencies (Scotland) Regulations currently indicates that an

"adoption agency must provide the prospective adopter with-

- (a) written information about the child's background, parentage, health and mental and emotional development;
 - [...]
- (c) a copy of the report as to the health of the child obtained under regulation 7(1)(d)(i)"

As Regulation 3 indicates that these regulations operate subject to the three sets of regulations indicated, we consider that provisions for disclosing information prior to an adoption, as is the case currently, is covered sufficiently. Your views on our interpretation are appreciated.

Q1 – Given the interaction with other relevant regulations, have these regulations addressed all the issues currently being experienced by adoption agencies and adoptive parents with regard to medical information?

Regulation 4

4. No automatic right of access to information

Neither the relevant child nor the adoptive parents have an automatic right to access information about the health of the natural parents of the relevant child.

Regulation 4 ensures that neither the child nor any potential adoptive parent has an automatic right to information collected under these regulations. The APRG report recommended that "professionals should consider carefully the need to disclose such information to adopted people and adopters". The release of information about the natural parent should only occur where this is necessary to plan properly for children who cannot live with their birth parents. Representations from various medical organisations, as well as other interested organisations and individuals, indicated that this information should only be disclosed by and to those with a duty of confidentiality to the information. As indicated above access to this information is regulated by provisions in other sets of regulations.

Regulation 5

5. Disclosure of medical information about natural parents

- (1) Where an adoption agency has not been able to obtain the information specified in paragraph 32 of schedule 1 to the Adoption Agencies (Scotland) Regulations 2009, (whether there is any history of genetically transmissible or other significant disease in the family history of either the father's or mother's family) a registered medical practitioner holding any such information must disclose it to the adoption agency when requested to do so.
- (2) Any information disclosed to an adoption agency under this regulation must be placed on the case record relating to an adopted child created under regulation 2 of the Adoption Information (Scotland) Regulations 2009.
- (3) Any information disclosed to an adoption agency under this regulation must be treated by that agency as confidential.

Regulation 5 places a duty on any medical practitioner holding information indicated in these regulations to disclose that when all other attempts to get this information have been unsuccessful. Currently the information being sought is that at paragraph 32 of Schedule 1 of the draft Adoption Agencies (Scotland) Regulations that were published for consultation on 7 July 2008. This numbering will be addressed in the redrafting of the regulations and any reference will be updated accordingly. The information collected at paragraph 32 of Schedule 1 is "Whether there is any history of genetically transmissible or other significant disease in the family history of either the father's or mother's family". In drafting these regulations we have discussed this provision with various medical organisations who all indicated a desire that a decision on the extent of the information being disclosed remains with the Scottish Ministers. We are seeking views on whether there may be any other medical conditions which those involved in the process would like to see considered for inclusion as they would have a bearing on the welfare of the child. We propose either to indicate these in the regulations or make a Code of Practice.

Q2 – It is out intention to reserve the decision on the extent of the medical information sought under these regulations to Scottish Ministers. With that in mind, we would be interested in what information would be useful, and is sometimes not forthcoming, when collecting information to help in the planning for the child.

DISCLOSURE OF INFORMATION AFTER THE MAKING OF AN ADOPTION ORDER

In drafting the regulations we considered occasions where access to medical history may be required by an adopted person, such as where information on susceptibility to late onset conditions would be useful, or where such medical information may be required by the adopted person. In considering how the disclosure of this information may be regulated we drafted the following regulation, which is not currently included in this set.

Disclosure of medical information about natural parents after the making of an adoption order

- (1) After the making of an adoption order under the Act a registered medical practitioner of the natural parents may disclose to the registered medical practitioner of the relevant child information relating to whether there is any history of genetically transmissible or other significant disease in the family history of either the natural father's or natural mother's family ("the relevant information").
- (2) The relevant child's registered medical practitioner may disclose the relevant information to the relevant child where the relevant child has attained the age of 16 years, if in Scotland, or 18 years, if in England or Wales.
- (3) In considering whether to disclose the relevant information to the relevant child under paragraph (2) the registered medical practitioner must have regard to the welfare of the relevant child.
- (4) Where the relevant child has not yet attained the age of 16 years, if in Scotland, or 18 years, if in England or Wales, the relevant child's registered medical practitioner may disclose the relevant information to the relevant child only if the practitioner thinks it appropriate to do so.
- (5) In considering whether it is appropriate to disclose the relevant information to the relevant child under paragraph (4) the registered medical practitioner must have regard to—
 - (a) the age and maturity of the relevant child: and
 - (b) the welfare of the relevant child.
- (6) Where, under paragraphs (4) and (5), the registered medical practitioner thinks that it is not appropriate to disclose the relevant information to the relevant child, the practitioner may disclose the relevant information to the relevant child's adoptive parents.
- (7) In considering whether to disclose the relevant information to the relevant child's adoptive parents under paragraph (6) the registered medical practitioner must have regard to the welfare of the relevant child.
- (8) Any relevant information disclosed to the relevant child's registered medical practitioner under this regulation must be treated by that practitioner as confidential.
- (9) The consent of the natural parents of the relevant child is not required for any disclosure of relevant information under this regulation.

The provisions of this regulation would allow the GP of the natural parent to disclose information on their patient to the GP of the adopted person without first seeking the consent of their patient. It is envisioned that this disclosure of information would be instigated by the GP of the adopted person in the first instance. This regulation would also provide for that information being disclosed to the adopted person and/or their adoptive parents if it was considered to be in the interests of the child, with consideration to their age and maturity.

However, in discussion with the medical organisations it is clear that there is currently well established guidance and practice for the disclosure of this information. Where disclosing this information is in the best interests of the welfare of the adopted person a GP of the natural parent could disclose this information. The GP would seek the consent of their patient prior to disclosure, however, if this is not forthcoming, and the disclosure of this information is required for the welfare or treatment of the adopted person then this information can be disclosed without consent.

We have not included this regulation in the set of regulations due to the routes already available in terms of disclosing information. Given the established guidance and practice in this regard it is hard to see how the information can be withheld where the welfare and treatment of an adopted person is being considered. In balance it is felt that the consent of the natural parent to the disclosure of any relevant information should be sought first and that the public interest test should be carried out if consent is not forthcoming. It is not our intention to create legislation which could cut across current practice and potentially damage doctor patient relationships and confidentiality. We consider that strong guidance and possibly the issuing of a joint practice note informing GMC members of the new legislation would sufficiently address any issues currently experienced with respect to access to information after an adoption order has been granted.

Q3 – Bearing in mind the current guidance and practice for GPs and the right to patient confidentiality that everyone is entitled to, should this additional regulation be considered for inclusion, or would a joint guidance and/or practice note issued to GMC members be sufficient?

QUESTIONS

Below are the specific questions asked throughout the consultation paper. However, we welcome comments on all of the proposals and the processes which are proposed in these regulations and their interaction with other regulations.

- Q1 Given the interaction with other relevant regulations, has these regulations addressed all the issues currently being experienced by adoption agencies and adoptive parents with regard to medical information?
- Q2 It is out intention to reserve the direction of the extent of the medical information sought under these regulations to Scottish Ministers. With that in mind, we would be interested in what information would be useful, and is sometimes not forthcoming when collecting information, to help in the planning for the child.
- Q3 Bearing in mind the current guidance and practice for GPs and the right to patient confidentiality that everyone is entitled to, should this additional regulation be considered for inclusion, or would a joint guidance and/or practice note issued to GMC members be sufficient?

ANNEX A: THE ADOPTION (DISCLOSURE OF MEDICAL INFORMATION ABOUT NATURAL PARENTS) (SCOTLAND) REGULATIONS 2009

SCOTTISH STATUTORY INSTRUMENTS

2009 No.

CHILDREN AND YOUNG PERSONS

The Adoption (Disclosure of Medical Information about Natural Parents) (Scotland) Regulations 2009

Made - - - - - 2009

Coming into force - - 2009

The Scottish Ministers make the following Regulations in exercise of the powers conferred by sections 74(1) and 117(2) of the Adoption and Children (Scotland) Act 2007(1) and all other powers enabling them to do so.

In accordance with section 117(5) of that Act, a draft of these Regulations has been laid before, and approved by resolution of, the Scottish Parliament.

Citation and commencement

These Regulations may be cited as the Adoption (Disclosure of Medical Information about Natural Parents) (Scotland) Regulations 2009 and come into force on 2009.

Interpretation

In these regulations-

"the Act" means the Adoption and Children (Scotland) Act 2007; and

"adoptive parents" means persons who are to or may adopt, or have adopted, the relevant child.

Application

These regulations apply subject to-

the Adoption Agencies (Scotland) Regulations 2009(2);

the Adoption Information (Scotland) Regulations 2009(3); and

^{(1) 2007} asp 4.

⁽²⁾ S.S.I. 2009/....

⁽³⁾ S.S.I. 2009/....

the Adoption (Disclosure of Information) (Scotland) Regulations 2009(4).

No automatic right of access to information

Neither the relevant child nor the adoptive parents have an automatic right to access information about the health of the natural parents of the relevant child.

Disclosure of medical information about natural parents

-a) Where an adoption agency has not been able to obtain the information specified in paragraph 32 of schedule 1 to the Adoption Agencies (Scotland) Regulations 2009, (whether there is any history of genetically transmissible or other significant disease in the family history of either the father's or mother's family) a registered medical practitioner holding any such information must disclose it to the adoption agency when requested to do so.

Any information disclosed to an adoption agency under this regulation must be placed on the case record relating to an adopted child created under regulation 2 of the Adoption Information (Scotland) Regulations 2009.

Any information disclosed to an adoption agency under this regulation must be treated by that agency as confidential.

> [A member of the Scottish Executive] [Authorised to sign by the Scottish Ministers]

St Andrew's House. Edinburgh

2009

(4) S.S.I. 2009/....

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EXPLANATORY NOTE

(This note is not part of the Regulations)

These Regulations, made under the Adoption and Children (Scotland) Act 2007, make provision concerning the disclosure of information about the health of the natural parents of a child who is to be, may be or has been adopted.

Regulation 3 provides that these Regulations apply subject to the Adoption Agencies (Scotland) Regulations 2009, the Adoption Information (Scotland) Regulations 2009 and the Adoption (Disclosure of Information) (Scotland) Regulations 2009.

Regulation 4 provides that neither the child who is to be, may be or has been adopted, nor the adoptive parents of that child, have an automatic right to access medical information concerning that child's natural parents.

Regulation 5 provides that where an adoption agency has been unable to obtain information about transmissible genetic, or other significant, disease in the family history of the child's natural parents, a GP holding such information must disclose it to the adoption agency on request. That information is then held on the case record relating to the child. Any information disclosed by the GP must be treated, by the adoption agency, as confidential.

ANNEX B: RELEVANT SECTIONS OF THE ADOPTION AND CHILDREN (SCOTLAND) ACT 2007

74 Disclosure of medical information about parents

- (1) The Scottish Ministers may by regulations make provision for or in connection with disclosure of information about the health of the natural parents of a child who is to be, may be or has been adopted ("the relevant child").
- (2) In making regulations under subsection (1), the Scottish Ministers must secure that a person to whom information is disclosed by virtue of the regulations has a duty of confidentiality in relation to the information.
- (3) Notwithstanding subsection (2), regulations under subsection (1) may include provision enabling a person to whom information is disclosed by virtue of the regulations, in such circumstances and to such an extent as may be specified in the regulations, to disclose the information to—
 - (a) the relevant child,
 - (b) persons who are to or may adopt, or have adopted, the relevant child.
- (4) Regulations under subsection (1) may, in particular, include provision for or in connection with specifying—
 - (a) the descriptions of person by whom, and to whom, information may be disclosed.
 - (b) the circumstances in which information may be disclosed,
 - (c) the type of information which may, or may not, be disclosed,
 - (d) the circumstances in which consent to disclosure of information need not be obtained,
 - (e) the processing of information by a person to whom information is disclosed.
- (5) In subsection (4)(e), "processing" has the same meaning as in section 1(1) of the Data Protection Act 1998 (c. 28).

RESPONDENT INFORMATION FORM: DRAFT ADOPTION INFORMATION REGULATIONS AND ADOPTION (DISCLOSURE OF **INFORMATION) (SCOTLAND) REGULATIONS**

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.

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Name	:			
Postal Address:				
1.	(a) as an individu	(please tick one box) ial □ go to Q2a/b and then Q4 a group/organisation □ go to Q3 and then Q4		
INDIVIDUALS				
2a.	Do you agree to your response being made available to the public (in The 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 <u>one</u> of the following boxes)				
	Yes, make my respo	onse, name and address all available		
	Yes, make my respo	onse available, but not my name or address		
		nse 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	П		
	No	☐ We will treat your response as confidential		
SHARING RESPONSES/FUTURE ENGAGEMENT				
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 No			