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

RESPONSE TO CONSULTATION ON DRAFT REGULATIONS

The Scottish Government

Edinburgh, 2009

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Introduction

The Adoption and Children (Scotland) Act 2007 (the 2007 Act) received Royal Assent on 15 January 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the new legislation is commenced, the existing legislation - the Adoption (Scotland) Act 1978 (the 1978 Act) - will be repealed, except to the extent necessary to maintain the legality of those adoptions that have already been made under it.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.

This consultation dealt with the draft Adoption (Disclosure of Medical Information about Natural parents) (Scotland) Regulations. As these regulations are subject to affirmative Parliamentary procedures they will now be included in a single set of regulations with the Adoption (Disclosure of Information) (Scotland) Regulations. These regulations are designed to make provision for access for adoption agencies to specified medical information where this might not have been forthcoming during the normal procedure for collecting such information.

The written consultation ran from 19 November 2008 until 28 January 2009. We received thirteen responses to the consultation, five from Local Authorities, five from organisations in the sector and beyond and three from individuals.

Questions

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?

The majority of respondents generally agreed that these regulations addressed the issues currently experienced by adoption agencies regarding access to medical information. The respondents agreed that adoption agencies should first attempt to collect this information with the consent of the natural parents when preparing the adoption case, as required in the Adoption Agencies (Scotland) Regulations. However, respondents acknowledged the issues that were also raised by the APRG, that there are certain circumstances in which access to this information proves difficult, including where the natural parents are a) withholding the information; b) absent and cannot be found; c) deceased. Under these circumstances the respondents and APRG indicated that regulations are required and that this regulation addresses these issues.

However, some respondents did indicate that they were worried by the lack of acknowledgement of the medial adviser to the adoption agency in these regulations. The medical adviser already collates much of this information collected, with the consent of the parents, under the Adoption Agencies (Scotland) Regulations 1996, and they are likely to continue to do so in the future.

Some respondents made more general comments about the processes currently undertaken by adoption agencies and sought further information on the application of these regulations. One respondent indicated that some agencies do not request "Mother baby" and "Parental History" forms to be completed by the parents, and another suggested that the regulations will not address practice issues in adoption agencies. Respondents also questioned whether these regulations would apply only to adoption or whether they would apply in cases for permanent fostering or the new Permanence Order, and also whether the regulations would apply with respect to hospital records as well as GP records.

Scottish Government response

The Scottish Government are pleased that the respondents acknowledged the difficulties identified by the APRG and felt that these regulations would go some way to addressing these issues.

With regard to the role of the medical adviser not being explicit in these regulations, the Adoption Agencies (Scotland) Regulations 1996 require an adoption agency to appoint both a medical adviser and a legal adviser to the adoption panel. However, the regulations do not require the medical adviser to collect the medical information, instead the regulations indicate at regulation 9(1)(a) that it is the adoption agency which must *"so far as is reasonably practicable, ascertained the particulars set out in Schedule 2"* which includes *"a comprehensive medical report signed by a fully registered medical practitioner, including such details as the medical adviser to the adoption agency considers necessary in the circumstances of the child"*.

While the medical report should contain such information as the medical adviser considers necessary, it is the adoption agency which has a duty to collect the information. How the adoption agency collects that information in practice is a matter for the agency and it is likely that the medical adviser is the most appropriate person to do so. These regulations do not preclude the medical adviser from acting in this capacity. Indeed, as the regulations will be subject to the Adoption Agencies (Scotland) Regulations 2009, which will include the provisions for collecting this information with the consent of the natural parents, it is likely that, where consent is not forthcoming for any reason the medical adviser (who is likely to have been attempting to collect this information) would then be able to approach the natural parent's GP for the specified information without consent being granted. As the duty is on the adoption agency to secure this information in the Adoption Agencies (Scotland) Regulations, the duty must remain on the adoption agency in these regulations. How the agency collects this information is a matter for the agency itself. Guidance will be issued which will help support the role of the medical adviser and address any practice issues which remain.

Clarification was sought on whether these regulations will apply to permanent fostering or the Permanence Order. These regulations apply where, in planning for the adoption of the child, the adoption agency cannot collect certain specified information. Therefore, these regulations will only apply to adoption and not to Permanence Orders or permanent fostering placements. 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.

Most respondents indicated the types of information which would be useful for adoption agencies to have when they are planning for children. This information included: neonatal and obstetric records; mental health information, Hepatitis C testing; blood borne disease testing and risks (such as evidence of injection drug abuse) and annonymised strong family history of illnesses or conditions.

Some respondents identified that it would be hard to produce a comprehensive list of conditions, illnesses and diseases that should be disclosed to the adoption agency when a request is made to a GP, and that it would be inappropriate to try to do so on the face of the legislation. Instead it may be more useful for Scottish Ministers to issue a code of practice or guidance on the types of information which can or must be disclosed and to contextualise this with reference to the purpose of the information.

Scottish Government response

As indicated by some of the respondents, it would be inappropriate to attempt to place on the face of the legislation a list of the conditions, illnesses and diseases which must be disclosed. Instead the Scottish Government have indicated that information which would be collected under what is now paragraph 13 of Part III of schedule 1 to the Adoption Agencies (Scotland Regulations 2009, whether there is a history of genetically transmissible or other significant disease in the family history of either the father's or mother's family. The Scottish Government plans on supporting this requirement with the suggested code of practice or guidance and we welcome the initial indications from respondents as to what should be included. The supporting documents will be developed alongside stakeholders, including local authorities, the General Medical Council and medical advisers.

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?

The majority of respondents felt that the additional regulation was necessary, but that it would require redrafting to cover "the reality of practice in adoption". A number of respondents reflected that data protection is a "difficult and controversial area" for doctors and that legislation was required to compel GPs to release information.

However, both the General Medical Council and the Information Commissioner's Office welcomed the exclusion of the regulations from the drafted regulations. The Information Commissioner's Office indicated that access rights to information post adoption (as this regulation refers to) can already happen under specific circumstances. They felt that inclusion of the regulation would cause confusion with respect to data protection rights already in place and felt that the provisions would be better in guidance. The General Medical Council also indicated that access to this kind of post adoption information was already available on a public interest basis and that the duty of confidentiality to patient's records was a paramount concern. It was preferred that consent to such post adoption disclosure was sought first. Two other respondents reflected the duty of confidentiality to patient records and that guidance would be preferable.

Scottish Government response

Although most respondents suggested tat legislation was required in this area, we do not propose to include this regulation. Both the General Medical Council and the Information Commissioner's Office were not in favour of the inclusion of this regulation as it would not be in keeping with legislation, practice and guidance on data protection and patient confidentiality. This regulation specifically dealt with access to information which had come to light post adoption, such as late onset conditions which may affect the adopted person when they are adults. Both the General Medical Council and the Information Commissioner's Office pointed out that this information was available already and including the regulations would cause confusion.

General comments

Some respondents made general comments about the regulations. These comments included: the absence of any mention of the medical adviser in the regulations; the term "birth parent" should be used instead of "natural parent"; the regulations would be better placed in one large set of regulations relating to adoption; that medical practitioners have a duty of confidentiality to their patients and that any information collected should not go beyond that required by adoption agencies

Scottish Government response

As explained above, the adoption agency has the duty to collect this information; the medical adviser currently collects the medical advice and these regulations will not change this practice.

As with other regulations, the term "natural parent" has been used as this is the term used in the primary legislation, we cannot change this term in these regulations.

These regulations are subject to different parliamentary procedure from the vast majority of other regulations, we will include these regulations with those other regulations subject to similar procedures.

Annex: Draft Regulations

Regulations form Part 3 of The Adoption (Disclosure of Information and Medical Information about Natural Parents) (Scotland) Regulations 2009

PART 1

DISCLOSURE OF MEDICAL INFORMATION ABOUT NATURAL PARENTS

Application

9. Part 3 applies subject to-

- (a) Part 2; and
- (b) the 2009 Regulations.

No automatic right of access to information

10. Neither the relevant child nor the adoptive parents of the relevant child have an automatic right to access information about the health of the natural parents of the relevant child(1).

Disclosure of medical information about natural parents

11.—(1) Where an adoption agency has not been able to obtain the information specified in paragraph 13 of Part III of schedule 1 to the 2009 Regulations(2), (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.

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

^{(1) &}quot;Relevant child" is defined in section 74(1) of the Act.

⁽²⁾ Part III of Schedule 1 is introduced by regulation 12(2)(c) (Duties of adoption agencies when considering adoption for a child) of the 1996 Regulations.