

# Cross Government Guidance – Sharing Information on Children and Young People

## Consultation Response

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## **BAAF Response to Consultation Cross Government Guidance: Sharing Information on Children and Young People**

The British Association for Adoption and Fostering (BAAF Adoption & Fostering) is the leading charity and membership organisation in fostering and adoption in the UK. We:

- promote the highest standards of child-centred policies and services
- speak out on behalf of looked-after children
- influence UK-wide policy and legislation
- provide much-needed information and advice
- promote greater public understanding of adoption and fostering
- support our members in their work

BAAF's main activities are the development, promotion and advocacy of best policy and practice; the provision of advice and information to our members and to the general public; training, consultancy and seminars; child placement services including the publication of our flagship monthly newspaper, *Be My Parent*. We also publish a quarterly professional journal, *Adoption and Fostering*, books and guides for professionals, academics, parents and carers and research studies. The main users of our services are our members comprising local authorities across England, Scotland and Wales, voluntary adoption agencies, independent fostering agencies and also individual social work, legal and medical professionals and carers. We are currently developing our service to Northern Ireland.

The views expressed here reflect a consensus reached through discussion within BAAF and through consultation with both BAAF's Legal Group and Health Group Advisory Committees.

We welcome this much needed guidance on an issue of fundamental importance to child welfare practice. With recent emphasis on the importance of multidisciplinary joint-working to safeguard children, it is an admirable intention to clearly and comprehensively specify principles for information sharing applicable to all services involved with children and young people. This document, however, seems to focus primarily on child protection issues, that is, on the *investigation* of abuse and neglect, and not on subsequent scenarios where sharing information may be crucial to a child's welfare, for example, in care proceedings, or disclosure of parental health information, and thus will be of limited benefit to fostering and adoption agencies.

The scope of this document needs to expand to include the full spectrum of areas concerned with the welfare of children, rather than simply a narrow focus on child protection. It must be cognisant of the much broader concepts of well-being as outlined in *Every Child Matters*. Specifically, expansion of this document to encompass all children in need, and to address the issues of children looked after, and those for whom adoption is planned, is essential. The key issue for these children, for which guidance is urgently needed, involves the tension between the parent's right to confidence versus the child's right to information about parental health and lifestyle which impacts on their own health.

The following comments note the areas which the guidance addresses well and highlights areas which require additional consideration.

### **2 Key Principles of Information Sharing**

This section is clearly written and helpful with regard to child protection, but needs to consider broader issues. To be useful for corporate parents concerned with improving the broadest range of

outcomes for looked after children, it needs to address complex issues which arise for looked after and adopted children.

### **3 Difficult Issues Practitioners Face**

The discussion of difficult issues is helpful, and the inclusion of concerns which go beyond child protection to more general aspects of a child's well-being, such as health or education, is particularly welcome. The importance of early intervention, not just for child protection, but also to achieve the five outcomes of Every Child Matters, is crucial in the arena of corporate parenting, where outcomes for looked after children have sadly been disappointing.

In paragraphs 3.3 and 3.5, the recognition that a failure to share information can be detrimental is welcome, but the guidance also needs to address the importance of obtaining and sharing information in situations that are less urgent than those involving child protection. For example, obtaining a comprehensive personal and family health history, and being able to share this with both professionals involved in planning and carers, is crucial for the long-term welfare and improved outcomes for looked after and adopted children.

The acknowledgement in paragraph 3.4, of the common anxieties practitioners may experience, grounds the guidance in the realities of practice.

### **4 Core Guidance on Key Information Sharing Issues**

The setting out of the law is helpful, and the detailed discussions of the power to share information, the duty of confidence and disclosure by consent are clear and relevant. However, the guidance does not, for the most part, address who does and does not possess parental responsibility, and therefore the entitlement to disclose information about a child. There is no mention of local authorities and prospective adopters having parental responsibility, and the need sometimes to override lack of consent by parents with parental responsibility, nor is an approach suggested for information sharing with foster carers who do not have parental responsibility.

Furthermore, to fully address information sharing relevant to all children and young people, both the body and Appendix 2 need to make reference to other relevant instruments such as the ACA 2002, Adoption Agencies Regulations, Fostering Regulations, and discuss issues such as special guardianship, private fostering, and childminding etc. Of note, is that the 2005 Adoption Guidance also fails to adequately address this issue and crucially, is inadequate on the subject of obtaining health information. There is also no mention in this guidance of statutory duties to gather information about prospective adopters/foster carers.

The statement 'Confidential information may be shared without consent where there is an overriding public interest in disclosure.' is made in paragraph 4.11. It would be very helpful to consider in detail the question of what is in the public interest, for situations extending beyond the urgencies of child protection and involving the broader aspects of long-term well-being, such as health and education. Quite frequently, the parents of looked after children disappear, making it impossible to seek consent to obtain and share parental and family health information, yet this information is vital to comprehensive assessment and planning for the widest long-term needs of the child. A broader perspective, which would consider improved long-term outcomes as specified in Every Child Matters as being in the public interest, would be welcome.

### **5 Information Sharing Checklist and Flowchart**

This section is most helpful, and the 'questions you need to ask yourself' provide a structured framework for practitioners to apply to the decision as to whether to share information. Bullet point two of paragraph 5.3 asks a key question relating to public interest.

## **6 Involving Children, Young People and Parents**

The focus on the development of respectful, co-operative relationships and the features of effective partnership working, with the recognition of the role of both resistance and unhelpful practitioner responses, will be very useful for practitioners. The detailed outline of how to go about gaining informed consent is similarly useful.

## **8 Promoting Health**

As stated previously, it is urgent that in Paragraph 8.5 examples concerning the public interest are expanded to address the longer-term well-being of children.

It is the opinion of the Health Group Advisory Committee of BAAF that the proposed change of practice for health professionals, outlined in paragraphs 8.7 to 8.9, is completely unworkable in practice. Health professionals will be reluctant to engage in any such vague exchanges of information as are proposed here. We consider that the application of a lower threshold for public interest in this scenario is misplaced and the interests of children would be best served if it were applied as earlier outlined.

We welcome the case examples cited, which are relevant and helpful, but would urge inclusion of an example concerning a looked after child, such as the following:

A 2 year old child is taken into care due to neglect and possible physical abuse. Before the full social and health history can be obtained, the mother disappears and intensive efforts to locate her are unsuccessful. The mother is known to use drugs and alcohol, but the duration and extent of use are not known, nor is it clear whether she used these during the pregnancy. The community paediatrician has concerns about the child's growth, as well as speech and language development. The Medical Advisor would like to access the mother's hospital records, including prenatal and delivery records, to obtain information about:

- possible prenatal exposure to tobacco, alcohol and drugs
- maternal tests for Hepatitis B and C, and HIV
- health including prenatal care and nutrition
- family health history

We are aware that the NHS electronic record system, National Program for Information Technology (NPfIT), is currently under development, yet there is no mention of it in this guidance. BAAF has been given the opportunity to comment on the processes involved in access to, and sharing of, health information for looked after and adopted children in the NPfIT. We believe it is of critical importance to the ultimate efficacy of the NPfIT that the same issues we have raised in this response be carefully thought through and resolved.

We are also concerned that this guidance may have the unfortunate outcome of deterring young people from seeking services such as mental and sexual health services if they cannot be assured that use of these services is confidential.

## **Summary**

We are very concerned that the guidance fails to adequately address the practice issues which arise for looked after and adopted children, of which the following are key:

- whether a child has the right to health information about self, when that information also involves others. Knowledge of a child's full health history, including prenatal, delivery, childhood immunisations, health and experiences, and family and genetic history, is central to

comprehensive high-quality medical care, yet is frequently unobtainable due to lack of parental consent, either deliberately, or through absence. Children come into care because of abuse, neglect, parental physical or mental illness or death, domestic violence and parental substance abuse, all of which may impact on the child's physical, mental, and emotional health, behaviour and functioning. Parents may withhold consent to disclose medical information as they do not agree to a plan for adoption. Parents may be absent, having abandoned their children, often because of substance abuse. Increasingly frequently, birth mothers who are substance abusers discharge themselves as soon as possible after delivery, then disappear, leaving their infant in hospital, with minimal medical and social information. Highly significant parental health information about any of these issues may be available in practitioner and hospital records, yet access is denied.

- the extent to which health information about a child may be shared with foster carers and prospective adoptive parents. Best practice in both health care provision for vulnerable children and ensuring informed consent, requires that comprehensive child and family health information be provided to prospective parents, yet consent to share health information may be lacking for the reasons stated above.

Medical Advisers to adoption and permanent fostering panels are faced with a dilemma on an almost daily basis. When they reveal all that is known about a child's personal and family health history to prospective carer/s, without explicit consent, they are at risk of litigation of breaching parental confidentiality. Yet they believe that it is in the best interests of the child for the prospective carer/s to be fully informed of the child's health history and needs, in order to determine if the placement can meet the child's needs, and minimise the risk of later disruption of the placement because the carer/s was not fully informed. Incidentally, this also minimises the chance of future litigation against the agency for not providing full information.

To complicate the matter further, when Medical Advisers seek advice about this dilemma, they receive conflicting legal advice from the General Medical Council, the Medical Defence Unions and legal representatives of Local Authorities and Voluntary Organisations. It would make such a difference if it were possible for agreement to be reached, and the guidance endorsed by the GMC and Medical Defence Unions as well as the Legal Society and CSCI.

BAAF has expressed concern about the need for guidance to resolve the dilemma between the child's right to know versus the parent's right to confidence, in multiple consultation responses and correspondence for over two decades, yet this issue remains unresolved. Since this issue is central to information sharing in health care provision for looked after and adopted children, there will never be a better opportunity to address it than this guidance.

This guidance must go beyond sharing information merely to protect children from abuse and neglect, to address the issues of accessing and sharing relevant health and social information to ensure optimal health and well-being in the broadest dimensions of children's lives.