

# Children in Scotland

16 January 2009

Patients' Rights Consultation  
FREEPOST NATN542  
Mailpoint 1  
Healthcare Policy and Strategy Directorate  
St Andrews House  
EDINBURGH  
EH1 0BR

Dear Sir or Madam,

## **CONSULTATION ON A PATIENTS' RIGHTS BILL FOR USERS OF THE NHS IN SCOTLAND**

Children in Scotland represents over 450 statutory, voluntary and professional organisations concerned with promoting the best interests of children and young people. We welcome the opportunity to comment on the proposed Patients' Rights Bill. We have chosen to respond by letter as we wish to make some general comments on how the needs of children and young people are reflected in the proposal.

1. **There is no specific reference to, or consideration of, children and young people in the document.** While we support the general direction and underpinning principles of the proposals, we believe that there would be practical problems in making these meaningful for children without clearer direction and duties. It is essential that information that enables children and young people to exercise rights and choices consistent with good practice and their legal entitlements is made available directly to them, using methods that are appropriate to their age and stage of development.
2. **It is essential to ensure that children and young people are informed about, and enabled to exercise, their proposed rights when they are patients.** It should not be assumed that: (a) the interests/decisions of children will always coincide with those of their parents/carers; or, (b) parents/carers will always have the capacity or

willingness to ensure that the rights of children and young people as patients are safeguarded fully and effectively in practice.

3. Guidance should be developed for health and other relevant professionals as to effective communication, meaningful consultation processes and active partnership with children as patients. The implications of the law as it applies to different ages and under various legal circumstances (e.g., looked after children) should be an essential component of this guidance.
4. Advocacy services or other support to ensure access to (and proper provision of) appropriate services should be available to parents/carers on behalf of young children or those unable to represent their own interests effectively-- as well as directly to competent young people.
5. In relation to patient responsibilities, such as keeping appointments, it must be recognised that children will not always be able to discharge these responsibilities independently of their parents. It is likely that the families who will have most difficulty in fulfilling these obligations are those who experience greatest social and economic disadvantage. It is vital that children are not denied access to essential health services as a consequence. This means that delivery methods should be considered such as provision of clinics in local health centres, home visiting and school based services. Where appropriate such issues should be considered within the *Getting it right for every child* (GIRFEC) framework.
6. The particular situation of children should be carefully considered in relation to issues of: access to records; privacy and confidentiality; data-sharing; informed consent; and, choice about treatment.
7. Opportunities to complain or to comment on care, both in terms of individual experience and in general, should take account of the particular needs and perspectives of children and young people.
8. Before legislation is drafted, it would be productive to consult with and involve children and young people in a *meaningful* manner about how they would best benefit from the proposals.

Yours sincerely,

MARION MACLEOD  
Senior Policy and Parliamentary Officer

Children in Scotland is Scotland's national agency for organisations and professionals working with and for children, young people and their families. It exists to identify and promote the interests of children and their families and to ensure that policies and services and other provisions are of the highest possible quality and are able to meet the needs of a diverse society. Children in Scotland represents over 450 members, including 90% of Scottish Local Authorities, all major voluntary, statutory and private children's agencies, professional organisations, as well as many other smaller community groups and children's services. It is linked with similar agencies in other parts of the UK and the European Union.

The work of Children in Scotland encompasses extensive information, policy, research and practice development programmes. The agency works closely with MSPs, the Scottish Government, local authorities and practitioners. It services a number of groups such as: the Cross Party Parliamentary Group on Children and Young People (with YouthLink Scotland) and the National Voluntary Children's Forum. Children in Scotland also hosts Enquire - the national advice service for additional support for learning, and Resolve:ASL, Scotland's largest independent education mediation service.