

September 2014

Dear Ms. McTaggart MSP

Re: Proposed Organ and Tissue Donation (Scotland) Bill

We welcome the opportunity to respond to the consultation on the proposed Organ and Tissue Donation (Scotland) Bill.

Children in Scotland is the national umbrella agency for organisations and professionals working with and for children, young people and their families. As an organisation we represent more than 400 members, including most 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.

Please note that Children in Scotland does not claim that our response represents the specific views or opinions of our wide and diverse membership. Also, we do not take a position on the proposed Bill, or to whom it should apply.

We have consulted with our members on the proposals through inviting them to respond to a short survey. This demonstrated diversity in opinion, both in relation to the overall purpose of the Bill, and in relation to specific elements such as the proposed inclusion of children in an opt-out system, and the age limit for this.

We received altogether 26 responses to the survey. All responses bar one were representative of the individual responding to the survey rather than of their organisation. It is important to stress that the survey cannot be taken to be representative of our membership.

- Of these 26 responses, 21 responded that they are in favour of the Bill, two were against, and two did not know. One respondent did not answer this question
- 17 of those responding believe that only adults should be automatically opted-in. Six responded that children should also be automatically opted-in.

- In a case of only adults being included in an opt-out system, 14 of those who responded thought that an age limit of 16 was appropriate. However, eight did not. Some respondents commenting on this suggested that 18 might be more appropriate for this form of decision making.

As this breakdown shows, there is divergence of opinion amongst the members who have responded to our survey.

Should work on the proposed Bill commence, we would like to stress the importance of taking into consideration children's rights.

We would propose, first of all, that a full Child Rights Impact Assessment (CRIA) of the proposed Bill be completed.

We would suggest that experiences from making similar changes elsewhere be taken into account. For example, a CRIA was undertaken for the implementation of a soft opt-out system for organ donation in Wales, and following this, a number of recommendations for actions were made.

The recommendations highlighted the importance of:

- Ensuring that any public awareness raising campaigns include work with schools and in other ways actively engaging with children and young people.
- Ensuring that systems storing personal details and preferences are secure and that information is held confidentially. This acknowledges the UNCRC Article 6 about children's right to privacy.
- Ensuring that public awareness campaigns take account of the specific needs of disabled children.

It was also recommended that the age limit for the legislation be evaluated within a reasonable timeframe.

We would suggest that these recommendations be taken into account in any further work on the Proposed Organ and Tissue Donation (Scotland) Bill.

Additionally, we would like to highlight the UNCRC Article 12 which stresses the right of children to have their voices heard on matters that impact on them. Based on this, we would strongly recommend that any further work on changes to the system of organ and tissue donation include meaningful engagement with children and young people, giving them a chance to have their voices heard on matters that will have an impact on them and their families.

Children in Scotland is the national umbrella 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 more than 400 members, including most 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 Europe.

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 also services groups such as the Cross Party Parliamentary Group on Children and Young People (with YouthLink Scotland). In addition, Children in Scotland hosts Enquire - the national advice service for additional support for learning, National Parent Forum Scotland, and Resolve: ASL, Scotland's largest independent education mediation service.