

Committee for Health, Social Services and Public Safety
Room B32
Parliament Buildings
Ballymiscaw
Stormont
Belfast BT4 3XX

14 August 2015

Dear Marie,

Re: The Health and Social Care (Control of Data Processing) Bill

Thank you for the invitation to provide comments in relation to this Bill.

The Office of Commissioner for Children and Young People (NICCY) was created in accordance with The Commissioner for Children and Young People (Northern Ireland) Order 2003 to safeguard and promote the rights and best interests of children and young people in Northern Ireland.

Under articles 7(2)(3) of this legislation, NICCY has a duty to keep under review the adequacy and effectiveness of law, practice and services relating to the rights and best interests of children and young people by relevant authorities. The remit of our Office is children and young people from birth up to 18 years, or 21 years of age if the young person is disabled or in the care of Social Services.

NICCY provided advice in relation to the consultation on 'Caring for You and Your Information' in 2014 in relation to the need to put in place robust safeguards which replicate good practice in from other jurisdictions, and the need to consider how these would relate to children. We do not feel that this advice has been reflected in the draft Bill, and are therefore reiterating our concerns to the Committee.

Clause 1: Control of information of a relevant person.

NICCY recognises the tension between the rights of an individual child, including their right to have a say and to have their best interests taken into account in matters concerning them, and the best interests of the wider population of children for whom sharing prescribed information may be beneficial.

Given that the proposals run counter to Article 8 of the European Convention on Human Rights it will be essential to put in place robust safeguards, which replicate good practice from other jurisdictions. In particular, the legislation should include a right for individuals to opt out, ie to refuse access to their identifiable information, as is the case in England and Wales. Consideration must then also be given to how children will be appropriately informed of this right, and express their preference on whether their identifiable information should be shared. Consideration should also be given to whether children would have the right to opt out or whether their right would be limited to having a say in the decision, and that a parent or carer would exercise the right to opt out on their behalf.

In conclusion, NICCY recognises that there are benefits to allowing the sharing of identifiable information, but remains concerned about the potential for these proposals to override the right of individuals to privacy contained in Article 8 of the European Convention on Human Rights and the Human Rights Act. The Bill should be amended to provide a right to opt out, and consideration needs to how this right may be exercised by children and young people.

Yours sincerely,

Mairéad McCafferty

Chief Executive

Northern Ireland Commissioner for Children and Young People