1. Introduction

The National Deaf Children’s Society (NDCS) is the leading charity in Scotland dedicated to creating a world without barriers for deaf children and young people. In Scotland, we have a dedicated team based in Glasgow led by Angela Bonomy, Director (Scotland & Northern Ireland).

NDCS provides a dedicated Children and Family Support Service across the country. Our current early years project, Everyone Together, delivers family sign across specific geographical locations. We also commission research to inform the sector and provides training for professionals as well as running a programme of events and activities for deaf children and their families aimed at building skills and confidence.

2. Context

We welcome the introduction of a single point of contact, a Named Person generally, but only if there is common understanding about the role of that Named Person and that it and the information sharing provisions which accompany the service are adopted universally in every local authority.

Information sharing and the assumption that Named Persons will be in a position to coordinate this information from across different services and act in the best interests of the child or young person will be crucial to them successfully completing their role. Information sharing across services is therefore crucial. However there is a need to address the technical and cultural barriers which often inhibit information sharing between statutory and non statutory services which can impact negatively on services delivery. At the same time this must not threaten the balance of promoting children’s rights and wellbeing and infringe on their right to privacy.

There is also the need to address the issue of parents’ empowerment and the importance of the home environment in advancing children and young people’s rights and wellbeing. A strong emphasis on how parents consent will be sought in terms of information sharing and how they will be enabled to become fully engaged in this process is fundamental.

3. The Bill

We broadly welcome the provisions of the Bill following the Supreme Court judgement on the information sharing provisions contained within the Children and Young People (Scotland) Act 2014.

We note that provisions around obtaining consent from a child or young person is not contained on the face of the Bill but will be included within the Code of Practice. We recommend that consideration is given to including the provision of consent and the duty to
inform a person that their information is going to be shared as part of the Bill. Please see our comments below on the issue of consent more generally.

4. Code of Practice

We note that the issues identified around information sharing by the Supreme Court are to be addressed by a Code of Practice (the Code) that will bring consistency, clarity and coherence to the practice of information sharing. Our view is that the illustrative Code in its current form is neither clear nor accessible to practitioners.

Professionals will be tasked with carrying out a balancing exercise between competing areas of law to ascertain whether information can be lawfully shared. We view this as an exceptionally difficult task for individuals to carry out therefore clear and concise guidance will be essential. **We recommend the Code is phrased in accessible language for professionals in outlining their duties under the Bill.** It will also be vital to develop illustrative case studies to inform practitioners through real life examples.

5. Consent

Named Persons may be relying on the consent of a child when sharing information pertinent to the child’s wellbeing. It is therefore vital that children and young people understand what is involved in providing consent. Professionals will require more clarity on what amounts to consent than is currently provided for within the illustrative Code. It should be clear that when professionals are seeking consent from a child or young person that the consent should be informed and explicit. Consideration should also be given to the higher threshold of consent that will be implemented by the General Data Protection Regulations in May 2018.

This will particularly be the case when seeking consent from an adult or young person with communication needs. It is fundamental that where a professional is seeking consent from someone who requires communication support that they obtain the same clarity on whether or not consent has been given as they would do if the person did not require such support.

The language and communication preferences of deaf children and young people varies considerably. This includes spoken English, British Sign Language (BSL), lip reading, Sign Supported English among others. Often the lack of awareness of these preferences can cause communication barriers for both deaf children and deaf parents. It is critical that high expectations of are placed in statute regarding ascertaining consent of every child and their families and that professionals are equipped to address the unique needs of those who are deaf. **We recommend this is addressed in the Code and subsequent professional resources.**

We regard the Bill and Code of practice in their current form as lacking clarity around the sharing of information without consent. We are concerned that the complex proportionality exercise outlined for professionals to undertake in this regard may result in the unintended consequence of practitioners being reluctant to share information and to merely undertake the more limited duty to ‘consider’. To address this it will be important that practitioners are clear as to what considerations they should take into account.

6. Wellbeing
Assessing whether there is a wellbeing concern with a deaf child may be more complex given the additional factors which may impact this such as language development and communication preferences.

Deaf children can easily become excluded within mainstream settings and require professionals to take a holistic and preventative approach to their wellbeing to reduce risks that this presents to their wellbeing. We are concerned that the current descriptions and examples of wellbeing do not fully support this preventative approach and may result in professionals having a continued focus on the more serious end of the wellbeing spectrum before they consider sharing information, such as a child protection issue.

Often information seeking to be shared will be health orientated yet the Named Person may not be a health professional. This could present a challenge to them in deciding whether such information should be disclosed.

We recommend that the Code explicitly includes the perspective of deaf or other disabled children through clear examples contained in an annexe. We would welcome the opportunity to support the development of these examples. We also recommend the Code highlights the need for professionals to take a rights based approach to identifying and addressing wellbeing needs through information sharing.

7. Role of third sector

We are concerned that there is no mention of Third Sector within the Code, particularly in relation to the assessment of wellbeing and obtaining consent. Despite the clear involvement of the Third Sector in developing and delivering targeted interventions, it is unclear whether they are included in the definition of a service provider. Similarly, duties on Third Sector organisations (particularly those without commissioned agreements with statutory services) in relation to information sharing also need to be clarified. We recommend that the role of the Third Sector is more clearly defined within the document so that all partners take an active role in implementing the Act and promoting the wellbeing of every child.

8. Training

As well as a code that is fit for purpose, we recommend the information sharing duties are accompanied by extensive training in wellbeing and confidentiality among professionals in statutory services, to ensure a clear understanding of appropriate and relevant information to consider sharing.

Lois Drake, Policy and Campaigns Officer