

Donaldson Report DHSSPS Room D1 Castle Buildings Stormont Estate Belfast BT4 3SQ

24 April 2015

To whom it may concern

NICCY welcomes the opportunity to respond to "The Right Time, the Right Place" an examination of health and social care governance arrangements for Northern Ireland. Health and social care services are integral to the wellbeing of all children and families and the report offers an important opportunity to consider how services can be improved and better outcomes for children can be realised. Please note that this response is not intended to be comprehensive but instead draws attention to a number of key areas.

Configuration of health and social care

As NICCY has previously noted¹, it is vital that the configuration of health and social care services in Northern Ireland reflects the needs of the population and we acknowledge the challenge this represents, particularly given the history of underinvestment in services. We would highlight that changes to the structure and organisation of provision should be underpinned by a rights based approach to health and that the planning, commissioning and delivery of services should be developed around the pathway or journey of the individual child and family. It is, of course, vital that changes to health and social care are focused on ensuring that children and young people can access high quality services, regardless of the time or day they are needed and regardless of their location in Northern Ireland.

In considering the commissioning of services, we note that integrated commissioning should sit alongside integrated service planning and must take full cognisance of the work of other departments and bodies, such as the multiagency Children and Young People's Strategic Partnership which is hosted by the Health and Social Care Board.

Child deaths and adverse incidents

NICCY notes with concern the report comments on the recording of child deaths where a child is in receipt of health or social care services as Serious Adverse Incidents (SAIs). It should be highlighted that the delay in the commencement of the child death overview function of the Safeguarding Board for Northern Ireland (SBNI) provides the context for how deaths are currently documented. NICCY has repeatedly raised concern about the lack of progress in

October 2012 submission to the Office of the High Commissioner for Human Rights on children and young people's right to health: http://www.niccy.org/publications/niccy-submission-on-the-right-to-health/

¹ January 2012 response to Transforming Your Care consultation: http://www.niccy.org/publications/niccy-response-to-transforming-your-care-consultation/

enacting this SBNI duty and while we recognise the difficulties created by the current arrangement, particularly the anxiety and distress this may cause families, any decision to end the recording of deaths through the SAI process must be replaced by an appropriate recording procedure. It is a matter of urgency that DHSSPS commence the relevant legislation and that the SBNI child death overview function is enacted.

It is important to note that the purpose of the child death overview function is to ensure that information regarding these tragic deaths is appropriately gathered, analysed and disseminated in order to reduce preventable or avoidable child deaths. The overview process should provide safeguards to ensure that where deaths require further investigation, including Case Management Review or effective liaison with coronial services, this occurs and that there is proper learning from deaths to reduce future incidents and to, for example, inform public safety messages and campaigns. The recently published "Why children die: death in infants, children and young people in the UK" report also calls for the establishment of the child death overview panel in Northern Ireland, in line with developments in other UK jurisdictions.

In considering SAIs more broadly, it is important that those which involve children but do not result in death or which involve adults with caring responsibilities for children (including those within mental health services), have a strong interface with SBNI processes to ensure that there is effective information sharing and learning from all cases which impact on children. The principle of ensuring clarity with existing reporting and review processes concerning children will also need to be addressed if a new structure such as an Institute for Patient Safety is established.

Complaints, inspection and the voice of children and young people

It is welcome that the report draws attention to the need to strengthen the voice of patients and NICCY highlights that this must, of course, include robust engagement with children and young people in all aspects of governance arrangements. For example, ensuring that children are aware of and have access to effective feedback and complaints mechanisms and that participation is a core element in any expanded remit for the Regulation, Quality and Improvement Authority (RQIA) which has previously included peer inspection as part of its work in children's homes. In relation to RQIA we note that any decision to extend the organisation's role requires thoughtful consideration and proper resourcing.

We welcome the review's commitment to strengthening whistle blowing protections and encouragement of debate on the introduction of an organisational duty of candour.

Data

NICCY welcomes the report's concern that data gathering, analysis and dissemination must be improved and we draw attention to the need to ensure that health and social care data must be properly disaggregated to allow meaningful analysis. In addition to ensuring information can be aggregated from individual service to local to regional levels, the system should also allow children's health and social care experiences and outcomes to be tracked by, for example,

² RCPCH and NCB (2015) Why children die: death in infants, children and young people in the UK

groupings such as for children with disabilities, for young people in care. It is again important that any developments take proper account of the work of the Children and Young People's Strategic Partnership in this area.

Equality implications

Children and families are often more reliant on health and social care services than others and this is particularly the case for those who are very young, have disabilities or complex needs or who are in need of particular support or safeguarding. It is therefore important that careful consideration is given to the adverse implications that these children and those in specified equality categories may be subject to due to changes in health and social care. These groups should, of course, also be actively engaged in consultations and ongoing work from the Donaldson review.

Please do not hesitate to contact my office if you require any further information.

Yours faithfully

Koulla Yiasouma Commissioner