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Dear Jackie

As Commissioner for Children and Young People, I welcome the opportunity to respond to the current consultation on the Review of Paediatric Health Care Services provided in Hospitals and in the Community. I wish to inform from the outset that this submission is not intended to be comprehensive but instead highlights key concerns. As Commissioner it is my principal aim, as set out in legislation, to safeguard and promote the rights and best interests of children and young people across Northern Ireland. As a signatory to the United Nations Convention of the Rights of the Child (UNCRC) the UK State Party, which includes Northern Ireland as a devolved administration, has agreed to uphold the rights of children and young people based on the Convention. We welcome and reinforce the importance of the consultation and the implementation of the Paediatric Review of Care having a child's rights and best interests as a paramount consideration.

The Integration of the UNCRC Principles into the Health and Social Care System

Article 24 of the UNCRC enshrines a young person's right to the best possible health and in line with other rights, reflects the principle of evolving capacity and addresses issues such as providing information and education to children, understanding children's capacity to make decisions and give consent, and ensuring access to complaints mechanisms. It is vital that the four articles which represent the guiding principles of the UNCRC are fully integrated into all government action to promote all young people's rights to the best possible health (Article 24). In particular, the Committee on the Rights of the Child in its General Comment No. 15, on the right to health, emphasised the importance of the best interests of the child as a basis for all decision making with regard to providing, withholding or terminating treatment for all children (Article 3). Article 2 sets out commitments to non-discrimination and Article 6 to the inherent right to life, survival and development. In respect to children and young people receiving healthcare services, this vision must be about maintaining the best quality of life attainable.

We would like to acknowledge the youth engagement work that has been done or planned across all phases of the paediatric review of care with respect to pre-consultation and consultation. Furthermore in line with Article 12 - one of the guiding principles of UNCRC - suitable mechanisms should be built into the health care system to uphold a child's right to be heard and for their views to be taken into account both in relation to their own care, and also more broadly, in informing service planning. This includes actively seeking the views of parents or guardians, where a child does not have the capacity to speak on behalf of themselves.

Investment for Change

We welcome the acknowledgement through this review that changes are needed in order for all children in Northern Ireland to receive a health care service where the care and treatment received is age appropriate, flexible and responsive to individual needs. Achieving the many positive and welcome proposals for health provisions for children and young people as set out in this consultation will require investment. We are very aware that when 'Transforming Your Care' was published in 2011, it referenced independent reviews which reported that levels of investment in children and family services in Northern Ireland was 30% less than in other parts of the UK. This disproportionate under investment needs to be addressed urgently, neither is it acceptable for some children's health care services to develop at the expense of others, and would be 'out of step' with the policy intent of ensuring "equity of access to specialist paediatric services for children". The 2011 and 2012 reports of young people's (16-21 yrs old) views on health and social care by the Patient and Client Council has highlighted reducing waiting times, increasing staffing levels and training, and modernisation of the system, as some of their top priorities for change. Unfortunately this yearly review does not seem to seek the views of those aged under 16 years old.

Age Appropriate Care

We note that it is proposed that Children (from birth up to 16th birthday) should usually be cared for by the paediatric team in paediatric settings, and those aged 16-17 years should be managed in age appropriate settings within either paediatric or adult settings. Although NCCY recommends that all under 18s to be treated in Paediatric Hospitals as a longer term strategic priority through commissioning, this progressive step is to be welcomed and reflects the recommendation set out in the 2012 RQIA 'Baseline Assessment of the Care of Children Under 18 Admitted to Adult Wards in Northern Ireland'. It is important that the 14 recommendations set out within the RQIA report are implemented. In particular, the need to set criteria as to when it is safe and appropriate for a child or young person to be treated on an adult ward, ensuring appropriate training of staff, having a dedicated ward or failing that, a bay for children and young people and a monitoring system across the Trusts

to track numbers and age of children when this occurs. In line with the consultation theme of offering 'age appropriate care', and being respectful of children and young people's evolving capacity and development as set out in the UNCRC, NICCY recommends that there are adolescent units within Children's Hospitals. Furthermore, we would call for dedicated hospital ward facilities for children with life limiting conditions.

Structures and Standards for Effective Change

NICCY welcomes the proposals set out in this consultation to establish a paediatric network and will be monitoring progress on this closely. There is an urgent need for a networked approach to the delivery of paediatric services, which will provide a structure to address existing issues within the system i.e. developing effective and integrated working within healthcare and community care and between them, multi-disciplinary team working, consistency in care pathways, ensuring and monitoring equitable access to services, including within specialist paediatric care and provisions of treatment close to home where this is appropriate.

NICCY has called for regional standards to be developed for children treated in adult wards and consistency in child protection policies across the Health and Social Care settings i.e. staff vetting and staff responsibility for children's protection, including when discharging from inpatient settings. We are pleased that the DHSSPS is also developing a framework for paediatric care medical standards as we are concerned that only two HSC Trusts classified their services as Specialist Paediatric Palliative Care Services. The joint Equality Commission and NICCY policy document, "Strengthening Protection for Children and Young People when accessing Goods, Facilities and Services (2013), has called for the inclusion of under 18s in the planned age discrimination legislation. This measure would give them the same protection from discrimination as over 18s, when accessing health and social care services. The report provides evidence of cases where children and young people have experienced difficulties in accessing age appropriate health and social care services (including mental health services). NICCY's Legal and Investigations Team has dealt with complaints and concerns around lack of services beyond a certain age for certain conditions e.g. a practice among some health professionals to discharge children with ADHD from children's services connected with ADHD, when they reach 14-15yrs of age which in reality leaves them without services. Furthermore NICCY has also dealt with cases with respect to poor or non-existent services for rare diseases.

Interface with other Relevant Policies and Strategies

We acknowledge the recognition given within the review of the importance of the interface between maternity, neonatal and paediatric care. This is something we have raised as an

area where improvements were needed. Furthermore, we agree that this review should not duplicate other policies and strategies such as the Maternity Strategy, Long-term Conditions Framework, UK wide Rare Diseases Strategy, Safeguarding legislation, policies and procedures, however these inter-related policy areas should inform service planning and delivery. On both counts we will be monitoring progress with interest.

We are pleased that the consultation has outlined plans to work more closely with the Republic of Ireland when a paediatric care specialism is not available in the Northern Ireland. However, in principle all sick children should be treated as close to their home as possible. Therefore it is important to ensure that our health and social care staff have the fullest range of specialisms as possible to care for and treat children in Northern Ireland, this is particularly the case for the most sick and vulnerable.

Transition from Children to Adult Services

NICCY published research in 2012 on the experiences of young people with learning disabilities making the transition from children's services to adult services (copy attached). The review covered a range of areas including young people's experiences of health and social care. Although not a general cohort of young people, some of the issues raised are likely to be relevant to all young people. For example, young people expressed a wish for greater communication between education, health and social care services; the wish for greater support for children making the transitions in and out of acute hospital care and equal access to support across Northern Ireland.

Final Comments

NICCY would like to see an action plan developed which is designed in such a way that progress can be clearly monitored to include a timeline against actions and budget.

This review is very welcome and we trust that it will inform investment decisions and offer greater clarity in budget allocation and expenditure for children's services. The 3 phase review extends over 10 years from 2014 however, we remain concerned about children and young people who are facing these issues now. The time frame for implementation of the proposals must be realistic but as quick as possible. In particular we are interested in more detail on the timescale for development and Terms of Reference for the Paediatric Network.

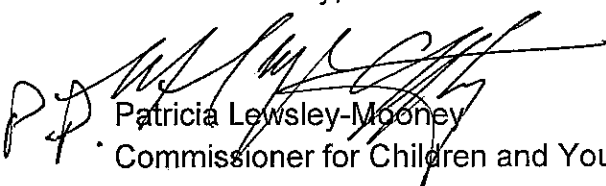
Please also find the following documentation attached:

1. NICCY's October 2012 submission to the *Office of the High Commissioner for Human Rights on children and young people's right to health.*

2. NICCY's January 2012 submission to the *Committee on the Rights of the Child for the General Comment on the right of the child to enjoyment of the highest attainable standard of health*.
3. ECNI & NICCY (2013) *Strengthening the Protection for Children and Young People when Accessing Goods, Facilities and Services: Recommendations for Reform*. Belfast, ECNI & NICCY
4. Lundy, L., Byrne, B., & McKeown, P. (2012) *Review of Transitions to Adult Services for Young People with Learning Disabilities*. Belfast, NICCY.

I look forward to speaking with you about this review of paediatric services, including the areas raised above, when we meet in February. In the meantime, don't hesitate to contact my Office if you require clarification on any of the issues raised in this submission.

Yours Sincerely,



Patricia Lewsley-Mooney
Commissioner for Children and Young People

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